

Angels Never Die

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INTRODUCTION

When we are born, and as we grow, we are naive to the world around us. Filled with uncertainties, we often stumble through life as best we can, hopefully learning from every twist and turn as we go. Nonetheless, those uncertainties can be daunting, as we become adults, especially when we become parents. Nothing can prepare us for this experience; there are no rulebooks, no guide to walk us through the process. There is no crystal ball that warns us of the events ahead that could alter our lives forever; and if there were, I'm not sure we would be better off for it. Faith is the only compass we have to find our way through all of life's perils.

I am no stranger to these perils; in fact, my life has been filled with tragedy. Yet I would not trade my journey for anything, for I have learned that along with great tragedy come great blessings. God blessed me and my husband with six children—four boys and two girls—who have brought immense joy to our lives. We would lose all four boys along the way, but through all the hardships, the endless nights of worry, the hundreds of trips up and down a lonely highway to hospitals, and the crushing financial burden placed upon our family, I have, through faith, continued to embrace my life. To this day, I continue to experience the blessing of my daughters and their children. This book is about my journey – one of love, loss and faith, and the importance of cherishing every moment shared with those we love, for as long as we're here on this earth.

Gwendolyn S. McNutt

DEDICATION

I dedicated this book to all those who have faced tragedy and devastation beyond what the average person can comprehend.

To my deceased mother and father, Mel and Clara Smith, who taught me the power of prayer and to trust in God - especially in the toughest of times.

To my four sons, Henry Junior, Adam Lewis, Randall Lavell, and Carl Edward, the most courageous boys a mother could have asked for. Even in their darkest hour, they knew how to live life to fullest.

To my wonderful husband, Henry McNutt, who has always been a faithful and dedicated father and husband.

To my two beautiful daughters, Laverne and Adrian. The love I have for you cannot be measured.

To my two handsome grandsons, Allen A. Watson and Clarence T. Johnson. You are my heart and I will always love you.

To my eight-sisters and four-brothers, thank you for your love and support over the years, and for your encouragement to write this book.

I thank all of you for being so strong through all of our adversity, and standing beside me as a pillar of strength. I could not have survived this journey without you. I love you all dearly.

Chapter 1

The Early Years – Gwen's Story

From an early age, I have strived to understand faith; it is a word that for many has little or no real meaning, while others could not exist without it. I personally cannot imagine a world without faith - faith in God, faith in family, faith in the human spirit. In my many years on this earth, I have been tested more times than I would care to remember. Ultimately, I know I would not be here today without holding on to the faith that was instilled in me from childhood. I have realized over the years that it is sometimes best not to question one's faith, but to simply believe. I have learned that as long as you have faith, you have a reason to carry on, a reason to live. Undoubtedly, without my faith in God, I would have ended it all a long time ago. I have questioned many times why God dealt me the hand that He did. I now know God only gives us what we can handle, and as long as you believe this to be true, you can endure anything. My story is a testament to how faith can carry you through the worst of times. I have also learned that by trusting in God, and having faith in all He does, everything you experience can be seen as a blessing - even in death.

I was born Gwendolyn (Gwundalyn) Sue Smith, in Levesque, Arkansas, a town so small that if you drove down the highway and blinked you would surely miss it. The name "Gwundalyn" was given to me by my

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maternal grandmother, who it is safe to say, did not know how to spell that well. Neither did my parents, at that time, so they also failed to realize the mistake. It wasn't until I started grade school that my name was changed by the teachers - neither they, nor I, could remember how to spell or pronounce "Gwundalyn".

Both of my parents had been in relationships before they married. My father had three children from two previous marriages, and my mother had one. Together they conceived nine more. I was the youngest of thirteen, "the last pea in the pod".

It was 1954, and prior to the Civil Rights Movement of the 1960's; a time of great racial divide. My father was a sharecropper for a local farmer. Although sharecropping was not considered slavery, it wasn't far from it. All the supplies we needed to live were purchased through the farmer, which meant my father was always indebted to him. In addition, we rented a small, four-room blockhouse on the property. My father had to work hard and long hours to provide for his family, and given the circumstances, he did his best.

My most vivid childhood memories date back to around 1962. I was a little black girl who really had nothing to compare my life to, for we only knew other sharecroppers and their families. As a very small child, I remember days spent playing outside in the dirt and sand, followed by my mother washing and plaiting my short, coarse, jet-black hair. Often I would awaken to the aroma of my mother's homemade golden brown biscuits and the fresh eggs we gathered each morning.

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In those days, she cooked everything on our old fashioned wood-burning stove. I recall the flour that she used for cooking her biscuits sometimes came in large cloth bags with multi-colored patterns. Most were designed with flowers or stripes. After each bag had been emptied, my mother used the material to hand-sew dresses and skirts for my sisters and me to wear. I often think about how lucky I was to have such a loving and wonderfully caring mother.

When I reminisce about my past, I always remember how interested my mother was in the church. Oftentimes, my father would follow us to church, whether he wanted to or not. His following us was undoubtedly at my mother's urging, and on those occasions, he always sat in the pew at the very back of the church. The problem was that in those days, bugs were members too; crickets, water bugs, spiders, you name it, they were there, and they took up permanent residence in the benches closest to the doors. Eventually the bugs became more than my father could bear. Gradually he moved closer and closer to the front, and before he realized it, he was caught up in a spiritual whirlwind that he could no longer control. Eventually, both he and my mother devoted their lives to God. I guess God has more than one purpose for every living thing - bugs included.

Like most Christians, Dad began to notice that the more people sinned throughout the week, the louder they prayed on Sundays. His own wary ways may have been the reason why he did not settle into any particular congregation. Even after he had accepted church as a profound part of his life, he visited several

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different churches and fellowshiped with a variety of people.

Ironically, it was his own need or compulsion to study the Bible, and through his meditation about his findings, that my father declared God had called upon him to preach. Ministers from various congregations in our area invited him to share their pulpit. From this, he became compelled to share the gospel and began taking it door-to-door. Eventually, after going from house-to-house and church-to-church, he felt the need to have a place he could call home. So he and his followers, mostly family, made great financial sacrifices in order to found the Congregational Church of Jesus Christ. My father was the pastor and my mother became a missionary.

While my father was finding his faith, mine was already being tested. I remember getting many spankings because of sleeping, playing, or talking in church. In those days, an adult could discipline their child any way they saw fit. Needless to say, I was often laughed at by the congregation whenever my father called me out for sleeping, or when my mother would walk from the "Missionary Board" and pinch me for misbehaving. When you are the preacher's child, you are going to be made an example.

I am not sure why that as children my siblings and I did not attend our schools plays or go to the school sponsored ball games. I never understood if my father thought it was wrong, or if it was just a matter of trying to keep us off the streets. I don't recall him ever preaching that those activities were a crime against God, or that a good education was more important. I do

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know that he was adamant about us not dropping out of school or us girls having babies too young. Given his past indiscretions, and there were many before he married my mother, it was ironic that he was totally against fornication and adultery.

Even though my father had turned his life around, spiritually speaking, I do recall a story that stands as an example of how, when you allow God to enter your life, your entire world can change. This is the story that was passed down to me.

My father was not always an honest man. In his younger days, he was a womanizer and a gambler, and he continued his contrary ways all through his second marriage to Ollie Mae. She didn't like the way he treated her, especially his sleeping around with other women and losing all of his money gambling. Early one morning, he crept into the house after yet another night of carousing. He quietly opened the door, hoping Ollie Mae was still asleep and wouldn't hear the squeaking from the old rusty hinges that held the dilapidated wooden door together. Unfortunately, for him, she was wide-awake and extremely upset. She was tired of his wayward ways and the way he treated her. He stepped one foot into the living room, not knowing that Ollie Mae was standing behind the door, icepick in hand and hungry for revenge. He had never realized just how jealous and angry she had become, but now, as she lunged for him, he knew she was intent on killing him. The icepick plunged into his chest, just an inch from his heart. At first, he was stunned and confused as to what she had just done; then she attempted to stab him again. Their fights had turned physical before, but never to

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this extreme. He managed to get the ice- pick out of her hand and body-slammed her to the floor. Then, gripping the wound on his chest to stop the bleeding, he stumbled out the door. He was trying to get to his car. She quickly got up off the floor, ran out after him, and attacked him again - this time from behind and with her bare hands. Enraged, my father looked toward the woodpile just a few feet away from the house. He noticed the axe he used to cut firewood laying in the pile. With Ollie Mae clinging to his back and blood still flowing from his chest, Daddy hastened to retrieve the axe. His plan was to cut off Ollie Mae's head. As soon as he picked up the axe, Ollie Mae took off running down the dirt road that led up to the house. He followed behind, and now they were both running down the dirt road, leaving a trail of dust behind. However, before he could get close enough to swing the axe, they passed a man with a pair of mules pulling a wagon down the narrow road that passed their house. At first, the man was confused and couldn't figure out what was going on. Then, when he heard them yelling and screaming at each other, he figured out there was a struggle. He turned the wagon around and hastened the mules to catch up to them. He got within a few feet from Daddy and Ollie Mae and could clearly see what was happening. The man knew them both, and their history.

"Just what I thought," he said, "It's a fight."

He saw Daddy swinging the axe in a rage as he ran toward Ollie Mae.

"Mel!" The man yelled from his wagon, "What are you doing with that axe?" Unable to get Daddy's

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attention, he yelled louder, "Put down the axe before someone gets killed!"

The man was Mr. Charley Brown, a neighbor who lived just a ways down the road. He would normally have his wife with him, but on this early morning, he didn't. Mr. Brown was hoping to make it to town by the time the manager of his business opened the doors. He used to say, "The early bird gets the worm."

Even though Mr. Brown kept yelling for Daddy to put down the axe, Daddy kept running toward Ollie Mae as though he couldn't hear a word Mr. Brown was saying.

Mr. Brown abruptly pulled back on the reigns to stop the wagon. Once the mules stopped, he swiftly jumped off the wagon and ran up behind Daddy, managing to grab him around the waist and pull him down to the ground.

"Don't do it, Mel! Don't kill your wife!" he yelled. "That will cause you more trouble than you can imagine! You will always be a murderer, and you can't change that."

He wrestled the axe from Daddy's hand and threw it across the yard, and then the two men got off the ground. It was then that Mr. Brown noticed Daddy's shirt was dripping blood.

"Why are you bleeding?" Mr. Brown asked.

Daddy replied, "That crazy stupid woman tried to kill me. She stabbed me with an icepick."

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“Well, from the look of it, you need to be going to a doctor before you bleed to death.”

My father was still angry, so Mr. Brown continued to talk to him in an attempt to calm him down. He finally convinced Daddy this was not the way to settle the problem. Meanwhile, Ollie Mae walked back to the house. It was quite clear how fed up she was with his messing around and not coming home until the wee hours.

Once Daddy calmed down, Mr. Brown climbed back up onto the wagon and headed to town. Daddy went back to the house, gathered a few of his clothes, and then got in his vehicle and drove off, never to return. He drove to the local clinic. Fortunately, the doctor was an old army doctor who didn't mind waiting on the black folks. When the doctor saw how deep the wound was, and that it was still bleeding profusely, he knew Daddy needed to go to the hospital. My mother heard what had happened to him, and she and some of her friends went to visit him there. After he was discharged, he and my mother cohabitated for a few months before getting married. Apparently, they already knew each other. After they got married, he found out that both my mother and Ollie Mae were pregnant! Perhaps this incident helped convince him that he needed to change his life. He totally changed his ways and became an honorable family man.

As children, we had very little time for sinful pleasures. We labored in the fields alongside our father. When we were not in school or working, we helped Dad tear down old houses for extra money or did chores

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around the house. Most of the time our father kept us so busy that by the time we finished our homework it was time for bed. Even on the weekends, we worked and Sunday service was often our only break.

Realizing that this backbreaking labor wasn't getting us anywhere, my mother convinced my father to find a way to quit sharecropping and save for a business of his own. Finally, the hard work paid off. Dad saved enough money to buy two businesses and a nice plot of land and a mobile home park. He owned a company that would move houses instead of tearing them down, and a small convenience store. Suddenly life got just a little easier. Although we all still worked very hard, we would occasionally find the time to enjoy just being a family. We learned how to let loose and have fun around the house, and after Dad's businesses began to do well, we were even able to travel. We went to Detroit to see my mother's sisters, to Chicago and St. Louis to see my Dad's relatives, and to Mississippi to see my grandmother. Life was good.

Then, in 1973, my father died suddenly of a heart attack. I was just eighteen. To say that this was a great devastation to my family would be an understatement. To us, it was as if God had died, that our world would end. For as long as I could remember, my father was the embodiment of the living Bible. If he said something was right, then it was right. If he stated that something was wrong, then it was wrong. He had been our father, our pastor, the leader of our lives, and the keeper of our souls.

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As for the church, I am sure that he was missed there as well. Nevertheless, in no time things got back to normal, or at least moving in the right direction. There was an assistant pastor at my father's church, but for some reason he was not chosen to take Dad's place. Instead, a new pastor emerged from among the lay-members. He was my father's nephew by his brother. The congregation felt that he was the most capable of taking on the responsibility. Some members also decided that since my mother was no longer the "first lady" of the church, they could be candid about what they really thought about her. One elder in particular saw fit to pick on her with a fervid fault-finding spirit. My mother somehow endured this persecution for about three years before using my sick grandmother as an excuse to leave the church. Mom's trip to Mississippi to see her ailing mother allowed her a respectable outlet for escaping the wrath of the holiest of holies. It was time to move on.

A couple of years after my father's death, I yearned to settle down. I had just turned twenty and found a job cutting soles at a shoe manufacturing company, but to me, settling down meant finding a wonderful, gorgeous, and hard-working man to marry and have children with. As it turned out, I would be one of the fortunate ones; however, my search for the ideal husband was not without complications.

My church did not allow its parishioners to marry outside our denomination. To meet someone within the church could take years. There just wasn't that many men to choose from, since the church was founded by family members. Most of its members were

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related in some way or another. It was like going to a used car lot filled with lemons. The thrill was gone before ever getting started.

In September 1975, my faith was undoubtedly being tested. A few of my girlfriends and I decided we'd had about enough of church. On one particular night, my friends and I took my mother's 1972 Oldsmobile for a ride. We drove to the St. Francis Fair Grounds. St. Francis was a small community just a few miles up the road. The Fair Grounds had carnival rides and my favorite, cotton candy. After enjoying a few hours of "girls night out", we decided to leave. We got into the car and began to drive away. When we drove out of the gate of the parking lot, we noticed a truck with the hood up, and a tall, dark, and handsome young man standing beside it. He was dressed all in white, with the exception of some type of a dragon design on the left leg of his pants and on the left side of his matching short-waisted jacket. The outfit seemed to have been tailored just for him and emphasized his perfect physic. He was alone and clearly having trouble with this truck. As we pulled up to see if he needed help, he glanced up and looked at us through the windshield. Instantly, our eyes met. The light from the moon illuminated his beautiful bright eyes as he walked toward the car.

He stood next to the driver's side door, towering over our vehicle. I rolled down the window and we began to chat, oblivious to the line of cars waiting behind us. In a deep voice, introduced himself as Henry McNutt, and then asked for my name and phone number. In a matter of seconds, I had a pencil and paper in hand. I don't even remember where they came from;

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they just appeared. The light from the moon above provided a perfect silhouette of what love must be. I knew beyond words that this man was my future. After he took my number, he walked back to the truck and managed to start it. He then drove off.

My girlfriends and I arrived home around eleven o'clock. Henry called shortly thereafter, just as he said he would. As he spoke, I pictured him in my mind. His voice made me melt. I said to myself, "This man is mine!"

It seemed like forever before I saw his face again, even though it was just the next day. Thoughts of my gentle giant floated through my mind as I longed to be with him once again. Simply talking on the phone was a task that took great effort on his part. He did not have a phone at home, and the nearest pay phone was at a local truck stop about five miles away. He did not own a car, so sometimes he would borrow his dad's truck, and other times he would walk the whole way. Fortunately, Henry's aunt was a telephone operator for the county and she connected us for free. We knew she often listened in on our conversations, because we could hear clicks in the background when she connected someone else, and even an occasional sigh. After a while, Henry started borrowing his dad's truck to drive to my house. In no time, we discovered how much we really liked each other, and it wasn't long after that before we fell in love. I began to invite him to visit my church, and although he was not a devout Christian, he would occasionally accept.

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Our pastor preached very hard against Christians marrying non-Christians. According to his teachings, if I married Henry, I would be a sinner. In addition, by keeping company with Henry, I would be drawn into his world, presumably one of sin. Even though Henry visited our church, the pastor continued preaching the same sermon to me; that Henry was a non-Christian and if we stayed together, I would always be a sinner in the eyes of the congregation. Henry had not been brought up in the church, and he continued to attend with me, despite the fact that they had condemned him.

There were a few Sundays when Henry and I had been riding around and arrived to church five or ten minutes late. On those occasions, my mother would be standing in the vestibule, waiting for us, so angry her face had turned a mottled blue. She would yell at us so loud that the whole congregation heard. Apparently, Mom wanted us to get there early enough to get the front pew; that way we could be "purged of our sins". Henry and I were mortified.

One time, when Mom was ranting and raving, I looked at Henry and exclaimed, "I can't take it anymore! We have to break up! We have to end our relationship!"

He grabbed me by the hand and pleaded, "No! Wait! Wait a minute! Don't!"

I turned and headed toward the front door of the church, leaving him to stand beside my mom. I felt so numb, not knowing what to do or say next. "Gwen," he shouted, "Don't leave!"

Although I was determined to walk away, something inside told me to turn and look at him. There

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he was, still standing beside my mother, and with tears in his eyes.

As I stopped and looked at him, ever so gently he asked, "What is it that I need to do? I mean, what do you want me to do?"

"I don't know, I don't know," I repeated. Deep down inside I wanted to say, "Ask my mom, she is the one who is bitching." Instead, I kept calm because I realized that my mother was only doing what she felt was right. Not to mention the fact that, even though I was twenty years old, if I spoke out to her, she would have backhanded me across the mouth.

That day, we entered the church together but sat apart. The service lasted about four and half hours. It was all I could do to wait for it to end. I only wanted us to have the chance to discuss the future of our relationship. Once the service ended, we swiftly walked to his car. Henry opened my car door for me, then walked to the driver's side and got in. As we sat there, we knew that we did not have much time to chat. We just sat there for what seemed to be hours, watching the church door, waiting for my mom to exit. I was not allowed to leave until she did.

Finally, I initiated a conversation. "You know, Henry, I've been thinking a lot lately about leaving home. My mother is always nagging me about our relationship and it's really starting to bother me."

Henry gazed into my eyes and said, "Gwen, look. You can come and stay with me and my mama if things get too bad for you at home." He told me how much he loved me, and then he made an announcement that

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literally shocked me to my bones. “I am only seventeen, and I still live with my mama. I have problems.”

He had problems! To my way of thinking, we both had problems. As if the church issue wasn’t bad enough, he had been lying to me about his age. The first night we had talked on the phone, he told me he was nineteen. Despite this, we both knew that our relationship had grown too deep for us to walk away. My mind began to race. I knew that he could not move in with my mother, and I did not have a place of my own. I thought about moving in with his family. Would it be a mistake? After all, I did not know anything about these people. I questioned whether they would even approve of me, considering my age; not to mention the fact that my parents had taught me that fornication before marriage was evil. How could this work out, my living in the same house with the man I love, and possibly in the same room, without sleeping together?

In the days following that conversation, I started to feel very guilty about our relationship. When Henry stopped by, I told him, “I can’t go on this way. Either we will get married, or we will have to break off the relationship. We’ve been dating for eight months now. It’s time for a change.”

Without hesitation, Henry looked me in the eyes and asked me to marry him. My reply was an immediate and emphatic, “Yes!”

Next, he called my mother in Mississippi, where she had first stayed with my ailing grandmother until she passed away, and was now visiting her sick aunt. Surprisingly, she was very happy for us and gave us her

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blessing. I never asked her why she had this sudden change of heart, but it was around the time she made her decision to leave the church. In retrospect, I suppose that since she was no longer bound and gagged by the self-righteous fervor that gripped the congregation, she felt free to give us her consent.

Chapter 2

Henry's Story - The Early Years

For me, the road to a faith-centered life was much longer, and had many more twists and turns, than Gwendolyn's. For unlike Gwen's parents, my mother and father were not overly religious; in fact, they were not religious at all. It was not until I met Gwen that I realized, and understood, the importance of having faith. Today, I know without a doubt that I never could have survived without it.

I grew up on a farm in Palestine, Arkansas. In those days, most black people who lived on farms were poor, and lived in homes furnished by the farmer. A few had their own land and a nicer home, but they were still struggling. My family, five girls, five boys, and our mother and father, lived on Mr. Wilson's farm. Our home, also owned by Wilson, was little more than a shack. Its five small rooms had no glass in the windows, so we had to place plastic over them in the winter to

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keep out the cold. I remember many a morning waking up to snow coming through the windows because the wind had blown the plastic off.

My dad was rarely home when I was a child, and I would later learn that while he was legally married to my mother, he also had several other families with several different women.

He was also an alcoholic and a major gambler. Occasionally he won, but more often than not, he lost. Like most poor people who gambled, he was always hoping for a lucky streak. And like most hardcore gamblers, when luck did not show up, he would drown his troubles in the bottle. In spite of his addictions, however, he was a hard worker and demanded the same of his children. After school and in the summer, we chopped cotton and picked okra. During the summer months, my two older sisters, my brother, and I also worked through a program offered by our school. We did everything we could to help Daddy make ends meet.

My mother made a little money cleaning houses for white folks. Sometimes, in lieu of money, she was given old clothes and shoes; one customer gave her a few ducks and chickens that had been in the refrigerator for weeks. They were not quite spoiled, but they had become so slimy they were hard to hold onto. Those that could be salvaged, mom seasoned and cooked. Those that were too slimy and unsafe for human consumption she threw out the back door for the dogs to eat. This would happen more than once.

As I stated, my parents were not at all religious when I was growing up; however, they did teach us to

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be thankful for all we had and to love and respect everyone. That said, there were some people even my parents had trouble respecting; the woman who drove our school bus, for example. My mother considered her very snobbish, and with good reason. When I was in junior high school, I didn't understand why my little sister, who was in the third grade, got on the bus in the morning wearing the clothes my mama had dressed her, but had a different set of clothes on when we returned home. When we asked my sister about it, she told us the bus driver had changed her clothes. I guess she did not like the way my mother dressed my sister. Had the outfit been nicer or newer than the ones my sister left the house with that morning, it might have made sense; but that wasn't the case. Either way, my mother thought the bus driver had some nerve changing her child's clothes.

It was no secret that we were poor. My older brother Eugene ran away from home because he wanted a better life. He felt that our dad had been throwing our money away for far too long. Between Eugene's departure and my father's extended absences, I became, at twelve years old, the man of the house. This meant I was responsible for much of the hard work necessary to maintain our home. It wasn't unusual for us to become low on food and firewood during the winter, and obtaining these provisions became my job. To this day I can remember how sore my armpits would be after a day of dragging tree branches to the house, then chopping them with an axe so they could be used for firewood. When there were no branches to pull home, I would go into the woods close to the house.

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There I would find old trees that had fallen to the ground. I would chop them up and carry the logs back to the house to burn, even if there was snow and ice on the ground.

In those days, families survived by putting up food for the winter, or canning. However, there were times when even these supplies ran out. One time, we were running so low on food that my mother decided to cook a slimy chicken one of the white folks had given us. She seasoned it as best she could, relieved that there was enough for all of us. But we kids had made up our minds that, no matter what, we were not going to eat it. Once the hen was done, Mama put it on a platter and placed it in the center of the table. The aroma was not all that appealing, and no one touched it. We just sat there, staring at it. Then our bellies began to growl. I got up and went into the kitchen for a glass of water. When I got back, I noticed that a piece of the breast was missing. I did not see who was eating it, or maybe I just did not want to know. From there I walked into the living room and began to pray for a miracle. I prayed that I would walk back into the kitchen and find something better to eat sitting on the kitchen table. Not long after my prayer, I turned around and I went back into the kitchen. I saw no miracle, but did notice that a leg and more of the breast had disappeared. Realizing this was the only food to eat, I immediately grabbed the thigh and another part of the hen before it was all gone.

Eventually, even the half-spoiled food ran out. Where we lived, there was no such thing as running across the yard to borrow a cup of sugar. We lived in the country and all of our neighbors lived miles apart. The

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grocery store was several miles away and across the creek. There was a dirt road, but it was often flooded. Sometimes we cut across a neighbor's pasture and waded across the creek to save steps and time.

One day, with no food in the house, Mama decided to take the long walk to the grocery store. She asked me to go with her. When we reached Mr. Walker's store, with no money in her pocket, Mama asked Mr. Walker to let her take the groceries on credit. He had done this before and she thought that he might be kind enough to do it again. Mama did not realize that she still had not paid the last bill. Mr. Walker, who also didn't realize that she owed him money, let Mama have the food. However, when he figured it out, he had what the old people called a verbal "field day". This was a local store, and a gathering place for neighbors to get together and talk about the news, weather, or just people in general. That day, several of Mr. Walker's friends were there when he looked my mama in the face and said, his voice escalating with each word, "Now, you go ahead and take this food, but you got to pay that bill! I can't keep feedin' your family for free! You take this and go on!"

My mother was so embarrassed. She grabbed her bags and ran out of the store, with me in tow. Once outside, she continued walking as fast as she could, the tears rolling down her face. I don't think she even realized food was falling out of the grocery bag she was carrying. I silently followed, feeling terribly sad for her. I picked up each item as it fell out and placed it in the bag I was carrying. By the time we got home, my arms were filled with groceries. I truly felt the responsibility

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of being the male left in charge. From that moment forward, I realized I had to do my best to salvage what was left of my mama's pride.

During those adolescent years, most of my clothes were hand-me-downs from the white folks whose houses Mama cleaned. One of her clients was a dentist. Many of the clothes I wore had been his, including the shoes. His shoes were so worn by the time I got them, they spilled over on the side and turned up at the toes, and the heels were always worn thin on one side. As I wore those shoes, I was unbalanced, and my feet leaned the same way the shoes did.

I remember one time when I wore a pair of hand-me-down golf shoes to school, their little steel spikes making a click, click, click, click sound as I walked down the hall. The principal, who was standing beside his office door, heard the strange noise and turned his attention to the kids passing by. "Hold up!" he shouted, "Everyone stand still!" Everyone stopped in his or her tracks. He listened for the noise once more, but because I too had stopped, he didn't hear anything. "Walk," he said. Then everyone began to walk, again, and once again he heard the noise. "Wait a minute!" he shouted again. We all stopped and he then made each of us walk in turn. "One-by-one," he said, "You walk; you walk; now, you walk." Eventually, he came to me, pointed, and said, "Now you."

I tried to walk on my tiptoes, but the shoes betrayed me. As soon as he heard the telltale click, click, click, click, the principal grabbed me by the collar and told me to get to his office. He explained that I could not

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wear those shoes to school because they were too disruptive. In my eyes, they were the prettiest shoes I had ever had, and as soon as I got home, I tried to pull the steel spikes out so I could wear them again. Needless to say, it did not work out.

There was a point in my life when I really hated to get out of bed to go to school. It just wasn't my thing. My parents did not care, though; they made me go every day, unless I was sick. I was a slow learner and had no interest in books. In spite of this, I was a hard worker. I never spent a day in jail; never did drugs or became an alcoholic. During my junior year, I became interested in playing basketball. I was very thin and stood six-feet, five inches tall. The only problem was, my school's coach had made up a squad of all white boys. In fact, no black boy had ever played on the team. I also knew I was going to have a hard time getting on the team because of my grades. On the other hand, I knew they needed help, because they were losing every game.

Finally, I summoned my courage and asked the coach to let me play. When he refused to have a black boy on the squad, I, along with a few of my black friends, talked to the principal. He sided with us, and replaced the coach with someone who was willing to give us a chance. With a lot of hard work, including running several miles each day, I became All-Star for the team. I won many trophies and had numerous fans in my hometown.

Some of my most important fans were in the classroom. People often talked about how ballplayers go through school without really earning their grades.

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Well, it is true. My teachers gave me good grades, even though I had never passed a test on my own. Sometimes, while in class, I wrote words from whatever I saw passing by the window. If I saw a Wonder Bread truck, I copied the words down on my test. This would go on throughout the entire test. Nonetheless, I often received a "C" or "B", sometimes even an "A"!

Teachers did this throughout my senior year. Because I was young and immature, I continued to enjoy playing basketball and never saw the need to crack open a book. Later, the news got out that I had a reading problem. Ironically, that year I was offered full tuition to a college. When my schoolmates' parents found out I could not read, several forbade their daughters from dating me, saying that I would never amount to anything. When I asked these girls out to the prom, they would say, "My mama told me to stay away from you." Each time I was disappointed, and each time I turned and walked away in shame. A few of the other girls did take an interest in me, but I had no interest in them.

Graduation was around the corner and the school basketball tournament was coming up. I really wanted to play in it, and I depended on my teachers and the coach to stand by me, regardless of my academic performance. But we had just taken our college exams and I did not pass. The one time I needed my teachers to help me, they did not. The first game day, I showed up dressed to play, but the coach made me undress. What a big letdown! To top it all off, the same teachers who had allowed me to get by without earning my grades now treated me like an alien. Whenever I asked them

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anything about the test, they would just look at me and turn their backs. After that, I was done with school. I dropped out my senior year, certain I wasn't going to pass anyway. I would not learn to read well until many years later, when, determined not to go through life illiterate, I took classes at night.

The course of my life changed the moment I saw Gwen sitting in her mother's car at the St. Francis County Fair Grounds. After we parted ways that night, I did not drive home. Instead, I drove to my grandmother's house because she had a phone. A couple of my uncles were there, sitting at the kitchen table. When I told them I had met a fine-looking girl and that she had given me her phone number, they did not believe me. "Give us proof," they said, so I pulled her phone number out of my pocket and made that long distance call. Gwen answered the phone with a sweet sexy voice. Unbeknownst to me, my uncles had gone into the living room and picked up the other extension. When I realized that they were eavesdropping, I put my hand over the phone and yelled at them to hang up. But their ears remained glued to the phone, so I told Gwen to hang on and rushed into the living room. I did my best to get the phone out of their hands, but nothing worked. I felt like I was dealing with two little kids. I got back on the line and told Gwen I would have to call her back. I knew this was not the last time I would speak with the woman of my dreams.

It had been dark at the Fairgrounds when Gwen and I were chatting, so it was difficult to see all of her. But, without a doubt, the little I had seen, coupled with that sweet sexy voice, made me want to see her again.

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After several days and a few more phone calls, I asked if I could come by to visit. She immediately said yes and gave me her address.

When I got to Gwen's home and saw her again, I realized she was even more beautiful than I had recalled, and intelligent, too. This girl was very well put together; she really had it going on. More determined than ever before, it wasn't long before I was able to buy my own car. I just knew this was a sure way of being able to see Gwen more often. Unfortunately, this was not the case. My dad's truck was always breaking down, and he would often ask to borrow my new car, usually after I had just spent several hours washing and waxing it before a date with Gwen. "Let me borrow the car to pick up some razor blades (or something else) from the store. I promise I'll be right back," he would say. He was always lying. Sometimes I believed him and sometimes I did not. What I do know is that he never brought my car back on time. There I would stand, all dressed up, looking out the front window or door of the house, hoping and praying he would come back before it was too late to see my girl. We had no phone, so I couldn't even call to tell her what was going on. Realizing my father was never going to show up on time, I decided to buy a Harley Davidson motorcycle. This was a sure backup plan, because I knew that an old humpbacked man like him could not ride a motorcycle. Many times, I took Gwen riding on the back of my Harley Davidson. Those times were made in heaven.

The way my dad treated me, I often thought, "Surely my Daddy knows I've grown up." I had now turned eighteen and was engaged to Gwen. After all,

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when was the last time he'd had to beat my butt for not feeding or milking the cows? And I no longer pretended to make a fire on chilly mornings when I was really still lying in bed. That had always infuriated my dad. When I was younger, and my dad was home, he would wake in the morning and call for me to get up and make a fire in the wood burning stove. Being a drunk, he was always cold, and he wanted to make sure there was a fire going before he got out of bed. One of the tricks I used to get out of this was to take the heel of one foot, while the other parts of my body lay warm under the covers, and stomp on the floor several times, as hard as I could. This created the illusion of someone walking to the stove in the next room. Over time, I had perfected my technique; Daddy would hear the stomps and think I was doing as I was told. A few minutes later, thinking I had built the fire, he would jump out of bed, grab his clothes, and run into the room where the heater was located. It did not take long for him to realize there was no crackling fire, just a big cold room that felt like an icebox. Daddy would become so angry, I swear you could heat the entire room with the steam coming out of his ears. It was as though he was about to turn into The Incredible Hulk. We both were glad when those days were over. My dad wasn't always the nicest man, and could be very abusive toward my mother and us kids as well.

With a life like mine, there were times I thought that my relationship with Gwen would never last. I wanted Gwendolyn to have everything a man could give a good woman like her. I knew that my education was less than adequate and my job—tearing down buildings--would not be enough to take care of a family.

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I had other odd jobs on the side, but none of them paid that well. To me, Gwen seemed much more advanced than I was. She had graduated from high school and had a job working at a shoe factory. But in spite of my doubts, I was sure of one thing: I had enough pride in myself to keep moving forward. I had experienced some good times, along with the bad, and I refused to dwell on the past or feel sorry for myself. Instead, I chose to look for a better life and reach for higher goals, and I had made up my mind that life would be with Gwen.

If someone asked to me to describe my circumstances at the time, I would have quoted Langston Hughes: "Life for me ain't been no crystal staircase." Little did I know that the strength I gained from my past would become the bridge that would carry me over the troubled waters of the future.

Chapter 3

And So It All Begins

July 4, 1976, was truly a day of fireworks, because it was also my wedding day. At twenty-one years old, I felt like Cinderella marrying her Prince Charming. Henry and I were so happy to be joined together "until death do us part". After our marriage, Henry moved from his hometown of Palestine, Arkansas to Wynne, Arkansas, about twenty miles away. There we lived with my mother for about a month. By the end

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of July, he was lucky enough to find a better job with a company that made copper. We now had enough money to buy our own used car and a brand new three-bedroom, two-bathroom mobile home. Although to some this may not sound like a major milestone, we were very proud of how far we had come. Life was already getting better.

This was a very nice house, especially for black people in the 1970's. So nice, in fact, that the real estate company that sold us the mobile home had it published in the town newspaper. It was unusual for a black man to buy a new home where we were from; everyone was so poor.

Now the real test had begun. How much could we bear of one another? Was it love, or just lust? We soon found out that our ways and thoughts were very different. If he was hot, I was cold. If I wanted the door left open, he wanted it closed. Sometimes, during what started out to be a simple conversation between us, it felt like Satan, or some evil spirit had twisted every word, as if we were possessed. By the time the words hit each other's ears, it was as if they were coming from some alien from another planet. Neither one of us understood a word the other was saying. During those times, we constantly fought over nothing. We found ourselves being jealous for no reason. We both started to think, "What have I done?"

I think one of the biggest mistakes we had made in the beginning of our marriage is that we quit going to church. The church did not seem to want to accept

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Henry, and that became our excuse not to go. Our faith was truly being tested.

Some of the worst arguments had to do with our relatives. I would say, "I don't like the way your mother treats me."

Immediately, he would say, "My mama treats you just fine." Then he would start in on my mother. "What do I think about your mama? She's nosey, always putting her nose where it doesn't belong... WITH HER NOSY SELF!"

Now the heat was on. We both would blow up as big as two Texas bulls, ready to knock each other's horns off. We were fighting for the honor of our mothers. Then, when it got to the point that we were nearly out of breath and on the verge of having seizures from anger, we often took the fight outside. We would throw each other's clothes out the door while yelling at the top of our voices. Even though Henry was much stronger, whatever "stone" he threw at me, I would throw it right back at him. I wanted to make sure he felt the same pain I did.

Our mobile home was parked in my parents' trailer park. There were only a few feet between each house. Whenever we argued, our neighbors would peep their heads out the window, or walk outside to watch the fight. It was as if we were their nightly entertainment. But although we had become this ringside spectacle, we never let the sun go down on our wrath. We always made up, and we always felt so ashamed and guilty for our actions. To say that we were confused is an understatement. We never wanted to be

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away from each other, yet, at the same time, when we were together all we did was argue. We loved each other, but it was apparent we had some growing up to do.

At the end of August 1976, I noticed that my menstrual cycle was not normal. I began to feel other changes in my body as well, and I had little doubt what they meant. I remember we were in the kitchen and I was serving up food from the skillet. This would be a good time to break the news to him, I thought.

"Henry, guess what?" I said; then before he could answer, I blurted out, "I think I'm pregnant!"

He turned toward me with a look of amazement and stammered, "What, what makes you say that?"

"Well, I haven't had a period, and there are only two days left in the month."

"Hum," he remarked, "it must not be mine."

He was just being a smart aleck, but the way he said it stirred an instant feeling of anger toward him. I wanted to take the spatula I had in my hand and pop some sense into his thick head. "I can't believe you said that to me."

Inside, I was gearing up for another one of our famous battles. Before I could respond to his remark, he walked up from behind and put his loving arms around me.

Realizing he had ticked me off, he said, "You know I was just kidding. Girl, that isn't anything but sweet music to my ears." He kissed me tenderly on the

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cheeks, then playfully reached down and rubbed my stomach, as if I was already showing.

I tried to push him away. “Oh, get away from me, you clown. I thought you were serious.”

He held on tight, placed his cheek against mine. We savored the moment. It felt as though we were suspended in time; a perfect oneness of peace and joy as we looked forward to the future.

I waited until the middle of October before I had a checkup. I wanted to wait for Henry to get a day off so he could drive me to the first appointment. We were both nervous when we arrived at the doctor’s office. I signed us in and we waited impatiently, anxious to hear what the doctor had to say. Finally, I was called into an examination room. Henry walked toward the room with me, but stood in the hallway until the doctor finished my exam. The doctor then opened the door and invited Henry in. Henry entered the room, anxiously anticipating the verdict.

“Congratulations,” the doctor said, and held out a hand to Henry, who shook it eagerly. “You take good care of her, Henry, and we’ll see you in a month.” We left the clinic and headed home, astounded by the doctor’s confirmation.

Although I was pregnant, I still had to go to work. My job required me to lift fifteen pounds of oval-shaped rubber sheets. I would stack the rubber by the dye table that served as my work station, then I would bend down and pick up the rubber from the stack I had created. I placed the rubber sheets on the table, and using a shoe dye, I would cut out the soles of shoes. Once the soles

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were cut, I would place them in another stack. This was my routine all day long, five days a week. Although it was labor intensive, I needed to keep my job. I reasoned that we could save the money I made for the baby, while Henry used his money to pay the bills. On the other hand, I was terrified that all the heavy lifting might cause a miscarriage. I was torn.

This inner conflict did not last long. It was the last Friday in November, and I had just finished work for the day. When the supervisor handed me my paycheck for the week, he told me not to come back. Everyone who worked in my department was getting laid off. We had run out of work, and although the supervisor said he'd call if the situation changed, the rumor was that the department was closing for good. As I walked out the door, check in hand, an overwhelming sense of hurt and helplessness consumed me. I got in the car and shut the door, my eyes filling with tears. Here I was with a baby on the way and the holidays right around the corner. I knew there would be more expenses than Henry could handle. I tried to fight back the tears, but the harder I fought, the more they streamed down my face. It just wasn't fair!

Driving home, all I could think of was Henry. Henry usually got home before me, and when he did, he would prepare dinner. Sure enough, when I finally made it home I saw his car in the driveway. I approached the front door reluctantly, thinking, *How am I going to tell him? This is too heavy a burden to put on his shoulders.* I opened the door and entered the living room, hoping to avoid Henry until I'd dried my tears. But he heard me sniffing and met me head-on.

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"I heard some noise," he said, trying to catch my eye. "I thought I better come and see what's going on in here."

"It's just me." I tried to speak as normally as possible, hoping he would not notice as I moved swiftly toward our bedroom. But he followed right behind me, down the hallway and into the bedroom. "I have dinner ready," he said, and I could hear the worry in his voice. "Are you hungry?"

"Yes, thank you," I managed to say, trying to hide my face as the tears began to flow again. But despite my effort, he got a glimpse of my wet cheeks. "You're crying!" he blurted out, confused.

"Yes," I sobbed.

"What for?"

"I have no job."

I could tell by the look on Henry's face that panic was taking over; he was experiencing the same feelings of frustration and worry as I was. For a long moment, we stood looking at each other in silence; then he said, "You know, you shouldn't worry about the few bills we have. I can handle them. Even if it means I have to do overtime or get a part-time job. You don't need to be working anyway, now that you're pregnant."

I was so proud of the courage he had just shown. Hearing those words brought me a sense of peace and security. With renewed invigoration, Henry turned off the stove and we rushed to the car to go pay bills. From that point forward, the secret to our stability was

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learning to budget our money. We learned to use his income where we needed it most.

During my first pregnancy I added sixty-five pounds to my five-foot-seven-inch frame. I had weighed 130 pounds on our wedding day, but as the scale crept to 195 pounds, it became difficult to get around. Finally, on Saturday, April 9, 1977, around 5:00 p.m., I went into labor. Thank God, Henry was at home. He rushed me to the hospital, which was only about five minutes away.

"May I help you?" a nurse asked as we entered the hospital.

"Yes," Henry gasped, "My wife is in labor!"

"Let me ask you a few questions," she said calmly, as if everything was normal.

We had to answer what seemed like a never-ending stream of questions about my labor pains. Next, she told me to walk up and down the hallway to make the contractions stronger. It seemed as though I did that for an eternity before I was given a room.

During my thirteen hours of agonizing labor, Henry sat beside my bed, trying to comfort me. Nothing worked. Holding my hand and rubbing my stomach, he kept telling me everything would be all right, but the more he rubbed, the more my suffering increased. To add to my misery, piercing throbs shot from the back of my legs and up through the upper portion of my body. It felt as though the baby was trying to tear its way out.

Finally, I started to dilate and was placed on a stretcher in the waiting area. As I lay there, the pains became unbearable. I tried to get the nurse's attention,

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but she was watching another patient. My mouth was so dry from all the huffing and puffing, it felt as though I had not had a drink of water for days. I called out, "Nurse! Nurse! Please give me some water!"

She calmly looked over at me and said that I was not allowed to have water, or anything else.

A few minutes later, she returned with a big bag, which appeared to be filled with water. Young and naïve, I thought to myself, "Maybe she'll give me fluid through an IV instead." She told me to roll over on my side, and I did, although I wasn't sure why. Suddenly, I felt this unwelcome intrusion up my backside. She then proceeded to give me an enema. I thought, "What are you doing? Stop messing with my butt!" As though I weren't in enough pain already, she began to stretch the anus a little wider while inserting the nozzle that ran from the bag of fluid. Uncomfortable and embarrassed, I asked, "What are you doing?"

"Oh, I'm just giving you an enema, honey. Just relax."

Relax? Really? Before she could finish, I felt this terrible need to rush to the restroom.

"Stop! "Stop!" I yelled. "I've got to go!"

"You need to wait, and let me finish!" she replied.

Extremely aggravated now, I turned my head and looked her firmly in the face. "Woman, if you don't let me go, I'm going to put everything right here on this bed." I jerked the nozzle out and ran straight to the restroom, barely making it in time.

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I was beginning to feel as though I had been worked over. I staggered back to my bed, hoping to get a little rest. I shut my eyes, hoping the labor pains would subside. I just knew that after everything I had released in the restroom, comfort was inevitable. I was wrong. I had only a brief moment of relaxation when it was interrupted by a horrific pain. I let out an ear-piercing scream that sent the nurse rushing to my side.

"It must be time!" I shrieked. I begged her, "Please, go get the doctor!"

"We'll take you to the doctor as soon as you're ready," she replied in the same infuriatingly calm voice.

"What are you talking about? I am ready!" I cried.

"No, you're not." she assured me. "Wait until your pains start to come about two minutes apart, then, you'll be ready," she explained. "But you're getting there."

I pleaded with her to give me something to ease my pain.

"We're not allowed to. It may interrupt your dilation." A few minutes later, she returned with a needle. Pulling back my gown, she rubbed my buttock with alcohol.

"Maybe she changed her mind," I thought.

She proceeded to give me a shot. I further thought, "Now that that's over, maybe I can get a little rest." Having felt the shot, I convinced myself that the pain was not as bad as before. Then, about ten minutes later, my contractions started coming every few

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seconds, just the way the nurse needed them to be. It was time to deliver. The nurse pushed me into the delivery room, where my doctor was waiting. I watched the doctor put gloves on his hands while the nurse placed a gas mask over my nose.

"Everything is going to be okay," I heard her say.

Instantly, I began to feel the effects of the gas. My body began to relax, and I could barely feel the pain as I heard the nurse telling me to push. I gave three good pushes. Almost out of breath, I went for the fourth. Then, a little head popped out. Within seconds, the body came out smoothly, and with very little pain.

"What a relief!" I heard the doctor say. "It's a girl!"

Groggy from the gas, I wasn't sure, but it felt as though she had been laid on my stomach before they took her away to clean her up and weigh her. My little girl weighed in at seven pounds and was nineteen inches long. I was so tired I could barely open my eyes.

A little while later, I was being pushed down the hall toward a room. I managed to catch a glimpse of my mother, who had made it back from Mississippi, and my gorgeous husband, who was standing beside her. They both had looks of joy on their faces that said, "All is right with the world." Comforted by the sight, I immediately dozed off, secure in the knowledge that my two favorite people were there beside me.

When I woke, Mother and Henry were each sitting in a chair beside my bed. "How are you feeling?" Mother asked. Before I could answer, she began to crack

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jokes. "I know it felt good going in, but it didn't feel so good coming out, did it?" She laughed, and Henry laughed along with her. I wanted to laugh too, but I was in so much pain I did my best to refrain from it. In fact, the pain was so severe I was afraid to urinate.

After sitting with me for a few minutes, Mother kissed me on the forehead, then left the hospital. Henry stayed by my bedside, caressing me. He was so proud. We held hands and gently kissed. Finally, he got up and walked over to one corner of the room to sit in an overstuffed chair.

"I'm so glad that everything turned out all right for both of you," he said softly, "because I was really worried at first. And," he added, chuckling, "I'm so happy that I'm not a woman!"

For a while, Henry sat in his chair and I lay on the bed watching television quietly. Finally, the pain subsided and I felt more alert. I pushed the call button and asked for the nurse.

She entered the room and asked, "May I help you?"

"Yes," I answered. "May I see my baby?"

"Well, I guess so. Is there anything else you need?"

"Yes, I want to breastfeed her."

The nurse explained, "She probably won't be able to feed very well right now, but you can still try. I'll get her for you in a minute." Her reasoning was that newborns sometimes have trouble finding or staying on

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the nipple right after birth – they may just lick the nipple at first. However, most babies begin to nurse within the first hour or so.

I could not wait to see her. Shortly thereafter, the nurse returned with the baby wrapped in a blanket. “Open your arms so you can hold her,” she said. I opened my arms to hold my baby girl for the first time. She was so tiny. While she lay beside me, I kissed and rubbed the soft hairs on her small head. Henry walked over and stood beside the bed, staring in amazement. She was so beautiful. This was the most wonderful blessing that ever could have happened to us. This little miracle had created a wonderfully loving and instant bond that made us a family. As Henry and the nurse watched me breastfeed the baby, the nurse smiled and asked him, “Now that you have this precious little child to support, does it make you feel more like a man?”

“Yes, ma’am, like a real man,” he said in a bragging sort of way. They both laughed and the nurse left us to be alone in the room.

Henry bent down and pulled the baby away from my breast. He secured her safely in his hands and brought her up to his face. He gently kissed her on the forehead. He then lifted our newborn child above his six-foot-five-inch frame and proclaimed, “Laverne, I shall call you Laverne.” He did this the same way Kunta Kinte’s father had on the television show, “Roots”. Admittedly, the way he did this was funny, but I was so sore I still could not laugh without hurting.

To keep from laughing, I said, “Man, quit playing around. I can’t believe you’re giving her an American

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name like Laverne and acting like you're back in the time of Roots."

"Woman, you just lie there and be quiet. I know what I'm doing," he boasted.

I could not contain my laughter any longer; I had to let go. Actually, I laughed and cried at the same time, because the pain was still so bad. I was so happy to see Henry bonding with daughter in his own special way. Finally, he placed her ever so gently back into my arms, then bent down and gave me a kiss.

Laverne was born on Easter Sunday, and it was so exciting, like celebrating two holidays at once. That evening, family and friends came to the hospital to see her, and three days later, my precious little daughter and I were discharged. We could not wait to take this little angel home so that we could watch her grow and develop into a beautiful human being. Henry and I were overjoyed with the prospect of starting our new life as a family.

Chapter 4

The Close Call

Laverne had just turned six months old when I decided to go back to work. I had heard that the factory where I used to work was hiring again. I knew I had left

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my position on good terms, so I convinced myself to fill out an application. Fortunately, I got the job as a packer. This would be a great help financially; plus Henry and I would have the same work schedules so we could ride to and from work together. We were lucky again when my mother volunteered to be our babysitter. She and Laverne grew very close during those years. Nonetheless, luck has a way of taking a drastic turn, and our faith was about to be tested once again.

One morning, we left for work as usual, leaving Laverne with my mother and an aunt from my dad's side of the family, who had come to visit. The night before Laverne had been running a fever, but she seemed fine by the time we went to work. I remember looking in on her before we left and seeing that joyful face and beautiful smile. I never feared leaving for work, knowing Mom would be there to take good care of her.

Henry dropped me off at work and went on his way. Then, around ten o'clock in the morning, I received an urgent phone call from my mother. She didn't go into a long explanation, just said I needed to come home. Hearing the unusual tone in my mother's voice, I knew something was seriously wrong. When I hung up the phone, I told my supervisor that there was an emergency and I needed to leave. He took one look at the expression on my face and let me go. I immediately turned and walked down the long hallway toward the exit, thinking, *How am I going to get there?* But apparently Henry had received the same phone call, because as I was exiting the building I saw our car parked in the front. As soon as I got in, Henry sped out of the parking lot. We didn't say much, but I knew we

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were thinking the same thing: *What could have happened to Laverne?*

When we pulled up to my mother's house, her car was gone. We ran to the front door and knocked, but there was no answer. Just a short distance down the road was a funeral home, and right behind that was a house belonging to mortuary's owner. In the rural areas where we are from, there are no fences to separate the homes, and nothing but open space between and behind the houses. So even from a distance, Henry noticed my mother and aunt getting out of my mother's car and getting into a long black Cadillac - the kind that carries family members to funeral services and gravesites. Henry wordlessly pointed in their direction, and I saw that my mother was carrying Laverne in her arms. We were petrified. Why were they at the funeral home?

Next, we saw a young woman run out of the house and up to the Cadillac. She had something in her hand, but from where we were standing we could not see what it was. We heard her shout as she handed the object to someone in the car, "Don't let her bite her tongue!" My mother took the pencil the young woman had handed her and placed it between Laverne's teeth to keep her from biting down on her tongue.

Henry and I took off running toward the Cadillac like two antelope being chased by a lion. We heard my mother cry out as she pushed the object into Laverne's mouth, "Please don't let her die!" When we reached the car, we saw Laverne was on my mother's lap in the front seat. She was having a seizure. I climbed into the front seat next to my mother, while Henry and my aunt got

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into the rear. Then the owner of the Cadillac sped off toward the town clinic.

We later learned that Mother was very well acquainted with the people who owned the funeral home, so when the seizures began, she immediately asked them to take her to the clinic. In her panic, she reasoned that it would be faster than waiting for an ambulance.

We arrived at the clinic and rushed inside. The doctor immediately had us take Laverne to the back for an examination. By this time the seizures had stopped, but he determined they had been caused by dehydration. He urged us to take Laverne to a children's hospital some fifty miles away, where she would get better care. Fearing she may have another seizure, we wasted no time. All the way there, as we drove down the long county road, I can remember hearing my mother and my aunt periodically cry out, "Please, God, spare this baby girl!" At one point, my aunt, a self-proclaimed missionary, bent over the front seat to lay hands on Laverne, who was lying in my lap. Laverne looked so helpless, and I was scared to death. I did not understand what was happening to my child.

Thankfully, our doctor had called ahead, and nurses were standing outside the hospital, waiting for us to arrive. A doctor was also waiting to take Laverne into an examination room.

After a few minutes, the nurse walked out into the hallway where we were standing to give us the breaking news. "Your daughter had a very high fever and it caused her to go into a seizure. As a precaution, to

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make sure that she will be okay, we have to admit her into the hospital for observation and further treatments."

"Can we stay here with her?" I asked.

"No, I'm sorry, but there aren't enough beds and we don't provide rooms for the parents to stay in. She is going to be fine. I just need for you to go back home and we will call you as soon as your daughter can be released."

"Okay, thank you, but I'll probably be calling you first to check on Laverne."

"That's okay, most parents do."

The thought of leaving my baby alone in the hospital overwhelmed me with a feeling of powerlessness. I could do nothing to stop what was happening to her. On the way home, my mother and aunt encouraged us not to worry. The doctor had assured us that we could call any time and come see her during visiting hours. The nurse had also told us Laverne would have a nurse with her at all times, and that they would provide us with updates and any information we may need.

The next couple of weeks were difficult for us. Henry and I consoled one another, saying over and over again that our little girl would be okay. Every day after work, my first priority was to call the hospital to check in on Laverne. The car we had at the time was not reliable enough to make the trip every day. Moreover, the doctor had assured us it would be better if we did not visit Laverne at the hospital, because if she saw us

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she would not want us to leave. He felt it would only make it more difficult for the baby. This seemed to make sense to us. I know it would have been sad for me to hear her cry and not be able to take her home.

Within two weeks, the nurse called and told us that our daughter was fine and we could come pick her up. When we arrived at the hospital, we walked into a large nursery filled with babies. Laverne was cradled on a nurse's lap as she rocked back and forth in a rocking chair. Even though she was only a year old, when she saw her father and me walk into the room, she stretched out her little arms for us to take her. We immediately grabbed her, smothering her with love and affection.

We were so happy to see Laverne that we forgot to ask the doctor if anything else was wrong, other than the original diagnosis. All we knew was that whatever sickness she had must have been cured; we were satisfied knowing that she would be fine. The doctor suggested we take her to our local clinic in two weeks for a follow-up. Thankfully, she has been healthy ever since.

This first experience with a sick child seemed, at the time, very traumatic. We had no way of knowing that this was just the beginning, a harbinger of things to come.

Laverne was back to her old self, energetic and filled with life. She brought joy and laughter into our home, as well as a sense of stability. She was a very curious child, and liked to figure out things for herself. If we turned our backs for a second, she was always doing

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something she shouldn't. At that time, her favorite toy was our keys, and her idea of "driving a car" was to stick the keys in an electrical socket. This was before child protectors existed for electrical outlets, and we thanked God that she was never shocked.

One day I was in the kitchen preparing dinner, and Laverne was standing beside me. Henry, who had just come home from work, plopped down on the living room floor to relax. Laverne ran to him and jumped on his stomach. She began to bounce up and down and playing with her father. All of a sudden, I heard Henry yell as he began to swat her little behind.

I ran into the living room to see what the heck was going on. "What's wrong?" I asked.

Laverne climbed down and ran away toward the television. "This little fool just spit down my mouth while I was yawning. I ought to spank you, again," Henry said as he reached for her. He swatted at her, but she took off so fast that he missed. "I believe that seizure made her crazy in the head," he said as he watched her scurry away.

Laughing, I replied, "Well, I don't think it came from the seizure. I think it came from her father."

"Well, what about you?" he asked. "She acts just like you, doing all kinds of crazy stuff!"

He looked over toward her and shouted as she planted herself down in front of the TV. "Don't you ever spit in my mouth again, or I'll give you a good whipping."

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While Henry continued with his rant, Laverne sat quietly in front of the television, staring at the screen. She looked so sweet and innocent sitting there, as though it could not have been her that he was talking about. Then, instinctively, Laverne glanced over her little shoulder, looking so sweet and innocent, as if to say, *"Are you going to swat my behind, again... me, your little angel?"*

Chapter 5

Making A Change

Later that year, Henry, and I had one of our many arguments before we left for work. Usually, my mother watched Laverne at our home, but it was snowing very hard that day, so we decided to drop Laverne off at her house, so that she would not have to drive. That evening, on the way home, the argument started up again. Once we got to the house, Henry grabbed some clothes and took off in our old Buick. I had no clue where he was going or where he would stay that night. I found out later that he got about half a mile from the house when the car became stuck in the snow. He was headed for Mother's place. She didn't live far from where he got stuck, so he decided to walk the rest of the way. In the meantime, I had already called to warn Mother that Henry and I had just got into a big argument and that he might be coming over. I asked her

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to please not give him the baby. I knew it would be his way of getting back at me.

To my surprise, Mother did not agree to this. "He is here right now. This is his baby, too. If he wants her, I am going to give her to him." Then Mother shouted at me over the phone, "You need to stop all this foolishness and let him back in that house!"

"But Mother, he started the whole thing! Now you're taking up for him? He even talked about you. He called you nosy, and he even talked about your nose." I said, trying to convince her that maybe she was doing the wrong thing by taking his side.

Without hesitation, Mother shouted, "Girl, you'd better shut your mouth and do what I tell you! He's gettin' ready to come home, and you better let him in. And you and Henry better not hurt that baby!"

Within a few minutes, Henry managed to get the car out of the snow and drove home with Laverne. He entered the house with our child in his arms. He handed Laverne to me, and then went back to the car and got his clothes. After that, we both sat in the living room, feeling stupid for letting things get out of hand.

I decided that maybe it was time for me to go back to church. I had even discussed the idea with one of my older sisters, and that Wednesday night, she came by the house and asked me to go with her. This would soon become a regular occurrence.

One night, as I was getting dressed, Henry stated, "You take Laverne with you. You're probably not doing

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anything but cheating out there anyway. I'm going to follow you one night and see what you're doing."

I ignored him and continued to get ready, then I picked up Laverne and left with my sister. For the entire fifteen miles to church, I wondered what had made Henry think I may be cheating on him; after all, he was the only man in my life. I had never given him a reason to believe I had some secret admirer or had been fooling around.

I was unhappy with this situation. The dilemma at home probably had a lot to do with the sudden change I was about to make in my life. That night, I became converted. I was once again bound to the strength and faith that had given my life direction in the past.

However, the troubles at home did not end. One evening Henry and I got into a big fight over nothing. I think it was because of the way I twitched my mouth while he was talking. He used to think I would do this in disagreement or something. He said it reminded him of his mean sister, the one he used to fight with all the time while growing up. Henry became so angry over what he thought I did, he threw me down on the bed and laid on top of me. He held me there with both his hands pressed against mine. His legs and knees held mine against the bed while the look of anger covered his face. Then, all of a sudden he released me. He got up and went into the living room. He sat down on the sofa, holding his head in his hands. I stayed in the bedroom with tears streaming down my face. I sat up on the edge of the bed and began to wonder why he was so evil. Then I began

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to wonder why he had released me. After a few minutes, Henry came back into the bedroom. I put up my guard, ready to fight him with all my might if I had to, but he had returned with a different attitude.

"Gwen, I'm sorry. This is my last time fighting with you. Something happened to me just then. While I held you down a spirit came over me. I don't know if it was God or an angel that told me to get up off you, that you are not my sister. He told me you are my wife, and to love you, not to fight with you. He said to grow up and be a man, and to leave that other stuff behind." Then Henry got down on his knees, took hold of my hands and said, "Please forgive me."

I was so angry I did not want to forgive him right away. Finally, I calmed down, but still kept my distance. There was no doubt he was serious about the angel visiting him in spirit, because we never had that type of confrontation ever again. Thanks to God for sending His angels. It was now time to have only love in our home, the kind necessary to raise a family, respectful of God.

I continued to attend church. Only, by this time, I had changed to a church just a few blocks from the house. I attended regularly, eventually giving my life to God, completely. I promised to serve Him no matter what my trials and tribulations may be. I continued to take Laverne to church, often inviting Henry to go with us; but he always turned down the offer, and always felt bad staying home alone.

"I get lonesome here by myself," he would say. "Why can't you just stay home sometimes?"

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One night, during a two-week revival, I deliberately asked him if he wanted us to stay at home with him to see what he would say.

“Yes,” he replied. “I think you should stay here a few nights. You don’t have to go to church every night. It gets kind of spooky sitting around here doing nothing but watching television and listening to the walls crack.”

“Well, the revival only last for about two weeks. Do you want me to leave Laverne here with you?” I asked.

“Noooo! I don’t want to keep that little sucker. I’ll never get any rest,” he said with a frown on his face.

“I thought you were lonesome?”

His only reply was, “Why can’t you just stay here with me?”

“All right, I’ll stay with you tonight. I won’t go to church. But if I stay with you, will you go to church with me one night?”

“Maybe I will” he replied.

Henry kept his word; he attended one night of the revival with me. However, once the service was all fired up, and the people started shouting, Henry got scared and left. He acted as though everybody there had lost his or her mind, and that he needed to escape. He went outside and sat in the car until everything had quieted down. Eventually, he walked back into the church with a look of concern on his face. He looked as if he was trying to figure out what was going on; had

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everyone there gone crazy? I kept my eyes on him the rest of the night, to make sure he was okay.

About a week after the revival, four of my sisters' husbands wanted to party. They asked Henry to ride with them. They ended up at a nightclub where many people, young and old, liked to hang out and party all night.

Henry confessed to me that on that night, he and his four brothers-in-law sat in front of the nightclub in the car, having a few drinks and smoking a little weed. He said he wanted nothing to do with the weed because he could not stand the smoke. Henry went out with them a few more weekends before finally deciding that this was not what he wanted to do with his life. One weekend they drove up to the front of our house. They honked the car horn and Henry went to the front door. They kept honking and waving for him to come out, but Henry just opened the door and stood in the entrance.

One of the brothers-in-law yelled out of the window, "Henry, come on, man. Let's go party."

"No thanks. I'm not going tonight."

"Man, you got to be kidding. We got plans for tonight."

"You've got plans for tonight. I don't."

"You're henpecked!" one of them shouted.

He snarled back, "You're right, I am henpecked. I am so henpecked the roosters in the barnyard keep flirting with me."

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Everyone laughed, and our brothers-in-law, realizing that he was not going, drove off. Henry turned, closed the door, then walked over and sat on the couch beside me.

"You know what, Gwen?" he asked.

"What is it, Henry?"

"I would rather stay home and be called whatever they want to call me, than sit in that car with the windows rolled up, inhaling that stinky smelling cigarette smoke and the alcohol, all mixed together."

We both laughed. I was glad he stayed. My faith in Henry, and in us as a family, was beginning to prove itself.

Chapter 6

The God Of Second Chances

In 1978, during the month of October, Henry came home from work with a stomachache. The pain began while on the job and continued after he got home. The pain was so severe, Henry, who never liked going to the doctor, decided to go to the clinic.

He was immediately examined by the doctor, who determined it must be indigestion and ordered him to take an antacid. We stopped by the drugstore on the

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way home and picked up a bottle. When we got home, Henry began to take the antacids by the handful. I warned him about overdosing. Despite my warning, Henry took the whole bottle of medicine. In spite of having taken enough medicine for five people, his stomach still hurt and he said he felt as though a knot had formed inside. At this point, who knew if it was from the pain or the medicine?

The next day he was so sick he didn't feel like getting out of bed. I took the car to work and left Henry at home to recover. I dropped Laverne at my mother's on the way. Even though he was in severe pain, he insisted on preparing my lunch. I told him not to worry about me, that I would be fine. I don't know if he forgot, or if he was just too sick to remember what I'd said, but he fixed me lunch anyway. He had managed to finish cooking and turned off the stove. He then started down the hallway to the living room. As he entered the living room, a few feet from the couch, he began to feel faint and very weak. Suddenly, he blacked out. Unaware of the time and place, he lay there in a deep sleep. He was lucky that he had turned off the stove before leaving the kitchen.

Around 4:15, I arrived home from work with Laverne. I thought he had decided to lay on the floor and rest. I began to caress his body and realized he was asleep. Finally, he woke up. Still drowsy, he mumbled, "Your lunch is on the stove." He thought I had just come home on my lunch break.

I knew he wasn't well, and placed my hand to his forehead. It was very warm.

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"You have a fever!" I said. "What's wrong? You haven't gotten any better?"

"No, I'm hurting all over," he muttered with a very weak voice. Still lying on the floor, he said he was afraid to move because of the pain.

"You just lie still, I'll call an ambulance."

It took two hours for the ambulance to reach our house, and by that time Henry had become numb all over. The paramedics suspected that his appendix had ruptured. They rushed him to the Baptist hospital, sixty miles away.

I rode in the front of the ambulance with the driver, leaving our little girl behind to stay with my sister, who had gathered outside with the crowd that the ambulance had stirred up. I knew Laverne would be safe with her aunt. As we drove away, sirens blaring, my sister prayed that we make it to the hospital in time for a successful surgery. Thankfully, the roads were clear and we made good time. Henry was immediately pushed into an emergency room. I watched as the nurse inserted tubes in his nose and stuck needles into his arms. His chest was hooked up to monitors to check his heart rate. Once they had hooked up the monitors and placed the IVs in his arms, the nurses pushed Henry down the hallway and into an operating room. They placed him under sedation and began surgery. After recovery, he was taken to a room on the same floor. When he finally awoke, I was standing beside him at the bed, patiently holding his hand. He later told me how much he really appreciated me for taking the time to look after him in the hospital. It would be three weeks

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before Henry was released. When he returned home, he still had bandages wrapped around his stomach. The hospital sent enough pain medication with him to last until he could see the doctor. Henry was so glad to be home with his family.

One breezy morning, while Henry lay in bed recuperating, my mother came by to check on him. As she entered the house, she hugged Laverne and me.

"Henry's fine," I told her, "He decided to stay in bed a little late this morning to rest. Do you want to see him?"

"Yes," Mother replied, "so I can look at him and know how well he's doing, for myself." She had a way of saying things that let you know she was in charge.

"Henry!" I yelled, "I'm bringing company." Reaching the bedroom, I knocked on the door. "I've got someone here who wants to see you. It's Mother."

"Okay," he said, "let her come in."

I let Mom into the room, and then left the two of them alone.

A few days later, while lying in bed, Henry decided to tell me about the conversation he had with my mother.

He said, "You know, when your mother came by to visit me after surgery, she told me I should thank God for giving me another chance, because I could have died when my appendix burst. If that had happened, she said I would have gone to hell. When she spoke those words, a chill came over me. I got very upset with her. At the

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time, I thought she was just being rude, but as time passed, I thought about what she had said and knew she was right. I know that I am still living a sinful life. I haven't allowed God to have full control of my life. The more I think about it, the more I want to change."

Hearing his confession, I rolled over and held him in my arms. I told him, "Henry, you have made me very proud, and I'm very happy to hear you say those words. All you have to do is ask, and God will send His angels, at any time, to give you the encouragement to do His will."

A big smile came over his face as I leaned over and kissed him goodnight. We fell asleep knowing we had something positive to think about: our faith was getting stronger, and as it would turn out, we would need it to get us through the coming years.

Chapter 7

Finding Faith In Our Love

During the three weeks Henry was in the hospital, I had plenty of time to think about my love for him. I often thought about what it would be like if he were no longer here. One day, while he lay on the couch in the living room, I looked at his frail body differently than I had before. He had shed nearly twenty pounds

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while in the hospital. The bandages that were wrapped around his stomach told the story of how much he had suffered. Despite what I was observing, something came over me and I began to ask all kinds of annoying questions. It was never my intention to hurt his feelings or doubt his love in any way. I'm not sure where it came from, but for some reason I felt compelled to ask such questions as, "Do you love me?" or "How much do you love me?" I don't think I was insecure; I just needed to hear him say those three words - I Love You. Even though he rarely used those words, Henry showed me plenty of affection. Yet, for some reason, regardless of the condition he was in, I needed reassurance.

Thinking back, I realize how ridiculous I must have sounded. He lay there, patiently listening as I ranted and raved about the importance of saying those words. Finally, he could tolerate the badgering no more.

"Yes, yes, yes! I love you!" he shouted. "Don't I show it? Out of all the things I do around here for you, can't you see it?"

Calmly, I said, "Yes, but I want to hear you say it, even if I don't ask. Is that so hard for you to do?"

"I do say it. I love you, I love you, and I love you! Now, is that enough?"

"No, it's not enough, because of the way you're saying it."

"You know I love you, so why do you keep driving me crazy with these annoying questions? Just because I don't say it, doesn't mean I don't love you. You know what, I'm sorry I'm not a very romantic person. I

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would like to be, but I wasn't brought up around all that stuff. I never saw my father being romantic with my mother. So how do you expect me to be any different?"

"Well, Henry, I'm just trying to understand. I guess I don't know your world very well. I always saw my parents show affection toward each other, and I'm just wondering, why can't we be the same way?"

"Well, maybe you need to wake up and smell the coffee," he blurted out.

"I don't understand. Why is it that you can easily say nice things about that girl you had a crush on in high school, but you have a difficult time saying them about me? From what you tell me, it sounded like it was easy for you to get into a romantic mood back then. Remember Anna, it seems like you can always find something nice to say about her?"

"I don't say any more about her than I do you."

It would probably have been best if the conversation had ended there, because from this point on, Henry really started to aggravate me.

"Yes, she was fine," he continued, "She had those fine hips, and she was very nice. She didn't act like you."

It felt as though Henry was doing his best to get back at me for asking him so many bothersome questions. I was convinced that he wanted to make me feel as miserable as he did about the non-stop ranting.

Henry aggravated the heck out of me talking about the girls who had crushes on him during his high school years. Though he made it clear that they were

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only crushes and nothing more, for some reason, I could not let go of the past. I realized he knew these girls before he had met me. So why was I questioning him about past crushes that were not even romances, and had nothing to do with the present? Despite his actions, I knew deep down inside that Henry loved me. I do not understand what was troubling me that day.

Now irritated in addition to his physical ailments, Henry felt compelled to keep talking about Anna, if for no other reason than to get back at me. Finally, jealousy took over my entire being. I had heard enough! Henry lay on the sofa just a few feet away, while I stood next to the fireplace. Suddenly, and as if an evil demon had taken over my body, I reached over, grabbed the clock off the mantel, and threw it at him. The clock hit his head and shattered into many pieces. Of course, he became instantly angered. He was too weak to fight back; however, that did not stop him from getting up off the couch to grab hold of me. Using all of my strength, I was able to stop him from doing anything physical. I then helped him back onto the sofa.

Realizing what I had done, I became extremely sad. I knew that type of behavior was not going to make our relationship any better. I felt as though the four walls were closing in on me. I could hardly breathe. I could tell Henry was struggling with this situation in the same way as I. I just wanted the walls to disappear. Even though Henry and I had our share of bad times, we had our share of good times, too. Yet, I felt as though there were always monsters or demons standing behind those four walls, forcing them inward, not wanting us to be free.

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I began to wonder, were our problems a result of us both having bad tempers, or was the problem that we were two different people from two very different worlds? *Perhaps*, I thought, *this is the time we needed to surrender to each other* I knew there would still be problems to work out and mountains to climb, but we desperately needed to do something. Many times, I wanted to walk away, thinking that maybe that was the only way the walls would tumble down; thus setting our spirits free. Neither one of us wanted to be the first to say goodbye. Perhaps that is why we stayed together. Regardless, it would be a lie to say that the first few years of our marriage were free of struggles. But we also knew we needed to give our love a chance, if for no other reason than the sake of our child. No one ever said it would be easy, and it sure wasn't.

I also began talking to God. *Here I am, going to church, and I've completely given my life to You. So why did I react to Henry like this? What type of spirit came over me? Henry has just started going to church. Was this incident going to drive my husband away from You, and me?* The more I thought about it, the sadder I became. I began to blame myself. Then, God quickened me. He let me know that I had to grow stronger, spiritually. I faced Henry and asked him to forgive me. Though he was hesitant to reply, I felt a burden had already been lifted off my shoulders. Our love would continue to be tested, but I believe God had heard and answered my prayers, for our love for each other would only grow stronger and deeper from that day forward. Faith in each other, and in God, was the glue that was holding us together.

Chapter 8

The Test Of Love

Like many young couples, as we continued on our journey together, our love was continually being tested. However, each time we passed the test, our love grew stronger.

In September of 1978, we learned that we were expecting our second child. Henry was hoping for a son.

Then, late one night the following June, during my ninth month of pregnancy, I began to feel labor pains. Henry was working the evening shift and had not made it home yet. I had just cleaned the house and was sitting on the sofa, watching television with Laverne. It was then that the pains began. I realized what was about to take place. Despite the pain, I became excited, knowing our family was about to expand.

I called Henry's job and asked his supervisor to call him to the phone. When he answered, I told him that I was in labor. I could hear the excitement in his voice when he exclaimed, "Are you serious?"

I could not help but laugh. "Yes, I am."

"Well, hang in there, babe, I'm on my way."

After I hung up the phone with Henry, I called my mother and told her the news. She was happy to know that another grandchild was on its way. A little while

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later, I heard Henry's car drive up, so I walked to the front door and unlocked it. When Henry entered the house, he was overwhelmed with joyful anticipation. I think he was more excited than I was.

He stood inside the living room door, breathless as if he had run home from work. After he began to calm down, he asked, "How far apart are your contractions?"

"I am not sure," I said, "but they are very close. Maybe about ten minutes apart, I guess?"

We had a bag for the hospital already packed. Henry grabbed the bag, picked Laverne up, and hurriedly put both in the car. Then he quickly returned to the house to help me to the vehicle. While helping me down the front porch steps of our home, a brutal contraction came, taking my breath away. It sent tears rolling down my face and I had to stop for a few seconds. Once the pain subsided, he continued to help me to the car.

Henry drove to my mother's house first. She was standing outside and he quickly got out the car and handed Laverne over to her. He then got back in the car and rushed me to the local hospital. When we arrived, he helped me inside, then I was immediately placed on a stretcher and rolled into the labor room. The nurses monitored me until I had dilated enough to be rolled into the delivery room. In no time, an oxygen mask was placed over my nose to help ease the labor pains. I'm not sure why, but as I relaxed under the influence of the oxygen, I began to hallucinate.

It was as if I was on a different planet. While in this state, I was unaware of everything or anyone

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around me. Suddenly, I saw a child. He appeared to be about seven or eight years old. Although he was in an inclined position, and leaning against a huge tree stump, I could tell he was very tall - a giant for his age. I stood directly in front of him as he sat there calmly and comfortably. His legs were extended, with one foot across the other. His hands were tucked behind his head. When he spoke, his voice was extraordinarily loud, but clear. I envisioned his voice could be heard all around the world.

Calmly, he sat up and began to speak about his perception of God's people. "If you walk this earth, you have the ability of performing whatever God requires. Your lives are capable of upholding God's purpose. After you have performed your duties and your body is tired, and ready to deteriorate, your souls will rest. Yet you will live and never die." He expressed his acclamation to God with handclaps. With each clap, it seemed as though he sent a shockwave across the nation as powerful as an earthquake. As he continued to speak, I stood before him, contemplating his insight.

The next thing I remember is the physicians shaking me. They called my name and tried to bring me to. Still dazed, I remember thinking, *What a deranged world I live in.* Once I was alert, the nurses rolled me from the delivery room and into a regular hospital room. They helped me from the stretcher and onto my bed. A nurse watched me until she was sure I was comfortable. For several minutes, in silence, I lay quietly, contemplating the illusion and strange feeling I had just experienced in the delivery room. Then I must have dozed off, and when I awoke, I saw Henry pacing

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the floor. He noticed I was awake and walked over to me. Standing beside the bed, he held and caressed my hand.

"Gwen, are you okay?" he asked.

"Yes, I feel fine," I replied, giving him a brilliant but weak smile.

Satisfied that I was okay, the nurse excused herself and left the room. Shortly thereafter, Dr. Burks walked in and stood beside Henry.

"Congratulations, Mrs. McNutt, you just gave birth to an eight-pound baby boy!"

After hearing the amazing news, Henry squeezed my hand tighter. He then bent down, pulled my hand up to his lips, and kissed it. "I am very happy that I have a son."

"Yes, I am too, darling, but don't forget, he belongs to me too," I teased.

Smiling, Dr. Burks chuckled and turned toward Henry. "What will you name him?"

"He'll carry my name, 'Henry'. Since he will be my oldest son, I'll name him Henry, Jr., but he'll be called Junior for short." Henry had such a proud look on his face that Dr. Burks and I looked at Henry and laughed.

"That's an imposing name," the doctor said, "He'll also have the first name of some great leaders. Maybe one day, when he grows up, he'll become a great leader, or some famous hero." Dr. Burks gave us another smile. "Well, I've got to go. Congratulations, again." He then smiled and walked out of the room.

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A couple of days later, Dr. Burks came to my room and greeted me with his ever-present smile. He examined me once more to make sure I was all right. The following day we were discharged, but before we left the building, Dr. Burks prescribed a particular brand of formula for Junior. He was to be bottle-fed. Dr. Burks requested that I bring Junior back to the hospital in two weeks for a follow-up.

When we returned to the hospital for Junior's examination, I was told that he seemed to be a healthy child. However, two months later, Junior was constantly crying and extremely restless at times. I became worried. Call it a mother's instinct, but deep down in my soul, I felt something was wrong.

As the days went by, he continued with his relentless crying. Henry and I took turns, trying to comfort Junior. We tried rocking him, carrying him, everything within our ability to quiet him. We were certain it was just a simple problem; we just didn't know what it was. We finally determined that perhaps he had gastric pains.

At first, we sought support and advice from our family and friends. Several offered advice about what they did with their infants to calm them. Some advised us to give him a nice warm bath at bedtime, a few said to keep him dry, others suggested we make sure he isn't hungry. We tried all of their remedies, and we gave him medication for gastric discomfort. At times, we thought the remedies were actually working. He would rest calmly for a few hours, only to begin crying again. A few more days and nights of continuous crying continued,

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for what appeared to be for no reason. We came to the realization that none of the remedies we used was helping him. We decided to take him to the clinic for a check-up.

The doctor did not have a clue what was wrong. Uncertain of the true nature of his condition, Dr. Burks determined one possibility could be that Junior was confused about day and night. He surmised that Junior slept more during the day, therefore leaving him awake and restless during the night. Because of the doctor's prognosis, we changed his routine. At first, it seemed that Junior started to rest a little better at night. But as time went on, we realized that even with the different routine, he was occasionally restless and did not sleep well, day or night.

On one particular night, Henry and I were especially exhausted from Junior's constant crying. We did our best to comfort him. We took turns sitting up, holding him in our arms, and rocking him. Henry had to be at work at 7:00 the next morning. Although he was very tired and worn out, he somehow managed to get dressed and go to work every day. Junior had finally quieted down, so Laverne and I continued to lie in bed. About an hour later, Junior started crying again. I lay there, tossing and turning with a pillow over my head, still tired from the night before. I resisted getting out of bed to attend to him as long as I could. Finally giving in to the crying, I got out of bed and picked him up from his crib. Forcing myself to keep my eyes open, I staggered into the living room. I felt like crap. I felt tattered and drained. As I observed the rooms, I could see the need for a good house cleaning. I hoped that I

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could get a little housework done before noon. I sat on the couch for a while and held Junior in my arms to calm him. When he finally quieted down, I placed him on the sofa to change his diaper. As I lifted his gown, I noticed a couple of small knots had formed on his tummy. I was even more alarmed when I saw blood in his stool. *First all his terrible crying, now he has blood in his stool! This is agony at its purest!* Scared, confused and exhausted, I began to sob. He had to go back to the doctor right away. Without giving it any thought, still in my house robe, I instinctively opened the living room door, rushed out of the house and down the little gravel road toward a neighbors. As I swiftly walked, I hoped and prayed they would be home to drive us to the clinic.

When I entered my neighbor's yard, gasping for breath, I saw there was no vehicle there. I rang the doorbell anyway. I then knocked on the front door, repeatedly, but no one answered. Filled with anxiety and disbelief, I turned and started walking down the little gravel road again, back toward my house. Tears began to steam down my face again. "Lord! I can't take this anymore!" I pleaded. "If you want Junior, please, just take him!" Finding release with those words, my reasoning came back to me. I dried my tears and asked myself what I was saying. Why did I say that? I did not even know to what extent he was sick. I rushed back into the house to make sure that Junior was all right. Eventually, Laverne awakened. She never knew the stress I had just gone through.

Henry came home late from work that evening. He went into the bathroom and took a nice warm shower, then got dressed. I placed dinner on the kitchen

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table and we sat down to eat. Henry took one bite of his food, and then looked over at me; he could tell I'd had a rough day.

"Junior has nearly driven you to kingdom come, hasn't he?"

"Yes," I answered. Then I smiled and said, "Why did you ask?"

"Because you look incredibly tired. You look as though Lassie has been chasing you all day, trying to get a bite out of your behind."

"Ha, ha," I laughed, "That remark was funny." I thought for a minute and replied, "Man, here I am still in a 'blue mood' from being pregnant and giving birth. Luckily, I'm able to put myself together before someone comes and takes me to a nursing home or to an insane asylum."

I then told Henry about the blood in Junior's stool, and of how restless he had been that day. I also pointed out that Junior had not put on much weight.

"Did he have a lot of loose stool today?" Henry asked.

"Yes, a lot more than usual."

"Well, maybe he is starting to have a bad case of diarrhea. It could be the reason for the blood in his stool. Let's put him on clear liquids for a while and see how things turn out."

In October of 1979, Junior was about four months old. One Friday evening, Henry and I were sitting on the living room sofa watching the six o'clock

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news. The newscaster reported on a certain brand of contaminated formula that was causing babies to have low weight gain, diarrhea, and blood in the stool. The government had ordered that it be taken off the market. Henry and I looked at each other in shock. It was the same brand we were feeding Junior!

The next morning I called Dr. Burks and told him what Henry and I had seen on the news. Concerned, he told us to change the formula immediately. The following week we took Junior to the clinic for a check-up. Dr. Burks discovered his iron level (hemoglobin) was low, and prescribed medication, hoping to help bring it back up.

We followed Dr. Burks' orders by changing Junior's formula and treating him with medication for his iron deficiency. Later, we took him back for a checkup and found that his blood counts were once again in the normal range. His restless nights had ended. We had finally found the answer to Junior's problems. He now seemed to be a healthy child, with boundless energy.

By April of 1980, I was four months pregnant with my third child. Junior, now ten months old, became very ill with pneumonia and we had to admit him into the hospital. It was very difficult to watch my child suffer with a cough and the pains he was going through. I felt helpless to do anything.

I can recall an incident that took place one night, just after midnight. Everything at the hospital had calmed down. The halls were clear, and most of the patients were sleeping. Henry Junior seemed very

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agitated, so I pushed the call button for a nurse. After a few minutes, no one had answered, so I pushed the button again. I was getting a little frustrated at how long it was taking, when finally a young blonde nurse walked into the room.

"May I help you?" she asked.

"Yes, Junior needs some assistance, he has become very agitated!"

The nurse calmly instructed me to follow her to the office of one of the interns on staff. I knocked on the door several times and a tall, handsome, middle-aged man opened the door. He looked at me with fiery red eyes. I could not tell if they were red due to a lack of sleep, or if he had been in the room drinking an alcoholic beverage.

"I'm sorry to bother you, sir," I said, "but my child needs some assistance."

"What is wrong with your child?"

"He is terribly restless and is agitated. I was hoping you could do something to help him."

The doctor followed me back to Junior's room. He immediately saw how miserable Junior was and ordered the necessary medication to calm him. A nurse administered the medicine, and a few minutes later, it seemed to help.

By the time Dr. Burks returned to the hospital the next day, Junior seemed to be doing better. During the three weeks he was in the hospital, he was treated with antibiotics and given several chest x-rays. Once he

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was satisfied that everything was fine, Dr. Burks reported that Junior's prognosis was good and finally discharged him.

Junior turned one on June 20, 1980. He had just learned how to walk. One morning he decided to follow his sister and me into the kitchen on his own. I opened the refrigerator door, without realizing that he was standing beside me, and mistakenly bumped his forehead. He did not cry, but quickly rubbed it. I picked him up and examined him but there was no knot or bruise. I kissed him and placed him back down on the floor. Minutes later, a huge knot did form on his forehead. Later, it turned blue. However, within a couple of days, it faded away.

Two weeks later, while I was giving Junior his morning bath, I spotted a large knot under the pit of both his arms, and on his groin. I became frightened. I did not understand why the knots had developed. Instantly, my mind took me back to the contaminated formula we were feeding him when he was an infant. At the time, I didn't think there was anything else to blame.

I watched the knots closely, but they never seemed to bother him. He kept laughing and playing as if they were not there. Henry and I were very puzzled about his condition and constantly wondered what could be going on with our son. We decided we had to take him back to the clinic.

Upon examining the knots, the doctor determined Junior needed a specialist. He set up an appointment for Junior at a children's clinic in Memphis, Tennessee. At the time, we were not acquainted with

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the city of Memphis, and we worried that we would not be able to find the clinic in time for his appointment.

Henry drove over to Mr. Henry Cunningham's home to ask for directions. He was an older man in his middle fifties, and most people in the church called him Brother Cunningham. Mr. Cunningham had done a lot of traveling, so we were positive that he had heard of the clinic and could tell us how to get there. Mr. Cunningham did us one better: he offered to drive Henry and Junior to the clinic.

When they left the house for the trip to Memphis, I prayed to God that He please take care of them and that He please not let Junior's condition be severe. As the day wore on, I grew very impatient; I wanted to know what the doctor was saying and doing to my child. Back then, there were no cell phones or text messages to let me know what was happening in real time; I just had to wait until he got home.

Late that afternoon, I heard a truck pull up in the yard. Laverne and I were overwhelmed with joy. "Daddy and Junior are home!" she yelled. She stood up on the couch so she could see out the living room window. Upon entering the house with Junior in his arms, Laverne ran up and grabbed her daddy's legs. Henry bent down and she hugged and kissed them both.

We got the children situated and Henry calmed down long enough to talk; he told me about their trip and what took place at the clinic.

"The doctors think that Junior may have leukemia, but they are not sure."

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I was stunned to hear this news. "What makes them think that?"

"That's not all," Henry added. "Tomorrow morning we have to take him to St. Jude's clinic, which is connected to the St. Jude's Research Hospital in Memphis. There are hotel rooms for the parents and patients to stay, should the doctors run into some kind of problem with the patient's disease, or if the patient has to have long-term treatments." He went on to say, "The good thing is, the doctor said that St. Jude's is a really good place for seriously ill children."

I sat there, speechless, but my mind was racing.

Henry took time off from work so he could travel with Mr. Cunningham to Junior's appointments. Since I was pregnant, we decided it would be best that I stay home with Laverne. As time passed, I could no longer agree to this. I worried too much about what was going on at the clinic. One morning, Laverne and I did not hesitate. We got up early and dressed to make the trip. Henry and Mr. Cunningham knew better than to debate our going.

There was barely enough room in the truck for all of us. Henry and I held the children on our laps. The children played and talked to one another while Henry and Mr. Cunningham talked about Junior's illness.

On the way there, Mr. Cunningham tried to comfort us. "Henry and Gwen, have faith in God. Just believe that Junior will be all right. I am a witness that God will be there for you in your time of need." He then quoted a scripture from the Holy Bible. We sat quietly, listening to his encouraging words.

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When we arrived at St. Jude's, we entered the building and walked into a large waiting area. Many of the children were bald, and most appeared to be very frail. However, some of the children, despite their illness, were able to jump and play; they did not appear to be as ill as the others. I wondered if this was the wrong place for Junior. He did not appear to be that ill, either. A nurse saw how nervous I had become seeing the children with baldheads and frail bodies. She came over and explained that the children who had lost their hair were taking strong medication, treatments for various types of cancer. I shuddered, remembering how I had watched my father struggle for his last breaths. It was awful to see these children in that condition, and I could not imagine what they were going through. I was so afraid for Junior.

The first thing they did that day was take Junior to a lab to have his blood count checked. We then went back to the waiting room until we were called for over the intercom. Eventually we were escorted into an examining room. The doctor, Dr. Wang, asked Henry to place Junior on the examination table. There were other doctors in the room as well. They were standing around the table, observing and following Dr. Wang's orders. The doctors slowly examined Junior from head to toe. They found other knots around his neck, or swollen lymph nodes, also known as lymph glands (lymph glands filter out and destroy bacteria and other harmful microorganisms within the blood cells). The physicians were able to feel the lymph nodes around Junior's neck, even though they were unnoticeable to us.

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The entire time, I was hoping and praying that he did not have any type of serious disease. Finally, I got the courage to ask Dr. Wang, "Will Junior be all right? Or will he have to go through some type of treatment?" I couldn't bear the thought of my son having to take some sort of horrible cancer medication.

Dr. Wang replied, "At this time, we can't say exactly what he has, or how serious the matter is, but we do know that the problem is not only the lymph nodes. We also checked his blood count. His platelet count is very low--only thirty-thousand, when it should run around four-hundred and fifty thousand. The good news is, whatever the problem, it doesn't seem to bother him very much." It was true; Junior laughed and played the whole time he was being examined by the physicians. The doctor chuckled. "He looks as though he could become a football player or maybe a truck driver. Right now, his appearance looks good."

The doctors decided to send him home with some type of steroid, hoping that would bring his blood count up.

We took Junior home and began to administer the steroids, but there was no change over the next few weeks. The medication was not working, though it did seem to increase his appetite.

In the meantime, Henry went out and bought a reliable used car. We needed it in order to drive Junior back and forth to the hospital without having to rely on Mr. Cunningham.

During one of the visits, Henry explained to Dr. Wang that it was getting close to my due date, and that

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while he was afraid of leaving me at home alone, the trips were becoming too difficult for me. He further explained he preferred to be there during my time of labor.

Dr. Wang looked at Junior, then glanced through his medical chart and made his decision. "I think he will be okay. However, if you notice any serious change, please give us a call or bring him back to see a doctor.

On September 19, 1980 at 8:35 p.m. our third child and second son, Adam, was born; he weighed in at seven pounds, eleven ounces, and was twenty-and-a-half inches long. Within the hour, Adam was brought into my hospital room, but to me it felt like forever. I couldn't wait to cuddle him in my arms and smother him with love. Henry sat by my side, overwhelmed with joy that he had another son. He could hardly wait for the same opportunity to hold and love Adam as he had his other children.

After what Junior had gone through with the bad baby formula, I definitely wanted to breastfeed Adam, and any other children we might have in the future. Within a couple of days, Adam and I were doing fine, and our doctors let us go home.

Junior and Laverne were happy to have another playmate and a brother to love. Henry and I were proud to have a daughter and two sons to love and to nurture.

Adam was the opposite of Junior. He never did much crying, and he was very easy to calm when irritated. Physically, everything seemed to be just fine.

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Two months after Adam was born, we received an appointment card in the mail, requesting that we bring Junior back to the St. Jude's clinic for a follow-up. I had recovered from giving birth to Adam and felt well enough to travel.

When we arrived for his appointment, the physician went through their normal routine of checking his blood count and then a physical examination. They immediately noticed his medical condition was getting worse rather than better. Dr. Wang informed us that they were still not certain of a diagnosis, but were still searching.

Hearing Dr. Wang's statement, I felt empty inside. We were hoping by this time the physicians would have found the answers to Junior's medical condition. Instead, there was nothing we could do but to return home and wait patiently.

Meanwhile, they continued to treat him with different medications while searching for a diagnosis.

Soon it was December, 1980, three months after Adam was born, and Christmas was fast approaching. Henry and I tried not to worry too much about Junior's medical condition. We wanted to continue our life as normally as possible. On Christmas Eve, Henry and I got up and got dressed, then my mother came over and watched the children while we went downtown to buy Christmas gifts. It was such a wonderful day. We were in the Christmas spirit and happy to be at home, rather than at the clinic.

On Christmas morning, our family came together in our cozy living room. We lowered our heads to thank

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God for allowing us to see such a beautiful day. Afterward, we opened our gifts; Henry and I watched as the children's eyes lit up with joy and happiness. Underneath it all, I could not forget about Junior's medical condition, and that we would have to return to St Jude in just a few days.

On New Year's night, around 9:30, Henry and I went to the church that my father once pastured. Every New Year's Eve, the new pastor and the lay members held a service at the church. They called these services "Watch Meetings". The idea is to watch the old year go out and see the New Year come in.

On this night, Henry and I made our resolutions, hoping for not only a change in our lives, but in Junior's health as well. We prayed that the physicians would soon diagnose his illness and find a cure. Around 12:30 a.m. on January 1, 1981, the church service ended with an inspirational prayer and our spirits were uplifted. Our faith in God and family had been restored.

Chapter 9

Fatal Signs

Soon after the New Year, we began to notice a change in Junior's medical condition - the appearance of Petechiae. Petechiae (pronounced puh-TEE-kee-ee) are

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small red spots that result from spontaneous ruptures of tiny blood vessels under the skin. His lymph nodes were once again enlarged, and he had ulcers in his mouth and frequent nose bleeds. In addition, Junior began to bruise easily. He seemed to always have bruises on various parts of his body, anywhere and everywhere he accidentally bumped himself. During this time, we regularly took him to St. Jude's, where the physicians also took note of this sudden and serious change in his medical condition. They were very concerned and searched rapidly for a diagnosis. After each visit, Henry and I would return home, hoping and praying that Junior's condition could be treated, and that the doctor's would find a cure.

Upon one of the visits to the clinic, Dr. Wang determined that Junior appeared to have a blood disorder known as idiopathic immune thrombocytopenic purpura, or ITP. ITP is a chronic disorder that can lead to easy or excessive bruising and bleeding. The bleeding results from unusually low levels of platelets — the cells that help your blood clot.

Now Henry and I were very worried. It was still unclear what damage that this disease may have already done to our son. Dr. Wang suggested that we treat Junior with the medication for the condition, in an attempt to prolong the platelet cell survival.

I asked Dr. Wang, "Will he be cured from this disease?"

"For now, let's continue with the medication, and we'll wait and see how things turn out." Dr. Wang paused for a moment. "But in the near future, we think

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that we may have to remove his spleen in order to correct some of his problems. This is a typical procedure for a patient with ITP. However, we don't like to remove the spleen unless the child is at least five years of age, due to the possibility of severe complications." Dr. Wang made it clear that Junior's condition was life threatening.

Having finished his diagnosis, Dr. Wang left the room. I think I knew from all he had told us that there was no sure cure. Junior sat on the examination table, laughing and playing, clearly unaware that he was sick. I became depressed and wished that I could do something to make him well. Even though we were relieved that the doctor had given his condition a name, we were still uncertain just how serious it was. I found myself sitting staring at the walls of the small room, trying to put the pieces together. A few minutes later, Dr. Wang returned to the exam room and gave us our next scheduled appointment.

Henry and I said very little on the ride home. We were both lost in our own thoughts as we tried to make sense of all Dr. Wang had told us. In contrast, Junior sat on my lap, talking and playing as if nothing was wrong. When we pulled up to our home, I was still dwelling on Dr. Wang's diagnosis and suggested treatment. The thought of removing Junior's spleen was driving me crazy. I couldn't believe--or, at least I did not allow myself to believe--that what the doctor had told us was true. Why were the physicians on Dr. Wang's team so convinced Junior had some awful disease? No one on either side of our family had any type of blood disorder. For the next few days, I couldn't seem to concentrate on

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anything; my mind kept drifting to all the things—real or imagined--that could have caused Junior to become so ill. No matter what the physicians told us, I could not bring myself to believe Junior's illness was life-threatening. It just could not be true! Henry and I were still only in our twenties and still learning how to deal with the responsibilities of our own relationship, so how would we deal with a sick child? The thought was terrifying. It wasn't long before the pressure became too difficult for me to handle. I tried getting away from it all by shutting myself in a closet. I wanted to stay in there and never come out. I even thought about suicide. I did not want to die; it just felt like we had already been through so much, and I did not want to face what was possibly ahead of me. I thought, *If I committed suicide, there would be no way I could return to earth and ask God to forgive me for my sins.* I had never done drugs or drank alcohol, but now I was considering both, anything that might take the pain away. But then my inner spirit would remind me that my family needed me now, more than ever. Once my faith kicked in, I was able to overcome my moral weaknesses and deal with the reality ahead.

No matter what Junior went through, he always kept the joy in his heart and a big beautiful smile on his face. His spirit could not be broken. Instead of Henry and me keeping him strong, he was the one keeping us strong.

By June of 1983, Junior, now three years old, seemed to be stable enough for a family trip. We decided to go to Madison, Wisconsin to visit Henry's oldest brother, Eugene. Eugene had left home when

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Henry was just a child, and I had never met him or his family. The brothers had not seen each other in years, yet it was as if no time had passed. Eugene showed us around his home and the large, beautiful swimming pool outside; then the two of them sat up for most of the night, laughing and reminiscing about the past. What a glorious night they had! After a couple of days, our visit was over and we headed home, but it had been wonderful to see them together. It also brought me great joy that, despite their harsh upbringing, Eugene was doing well. Like my Henry, he had become a man living on his own terms, not those dictated by the past. I was so proud of both of them.

Shortly after our visit to Wisconsin, we brought Junior to St. Jude's for a routine visit. During his examination, Dr. Wang discovered the lymph nodes under Junior's arms had grown even larger and said he needed to have one of them removed as soon as possible. "Even though we believe Junior has ITP, the only way we can be sure is to get a biopsy from one of the lymph nodes."

Henry and I listened to his suggestion, but I refused to go along with it. I was not convinced surgery was necessary and was afraid Junior would face complications while on the operating table. "It is urgent that we get a biopsy, and soon," Dr. Wang warned, "We need to figure out how to treat his condition before it causes him further harm. If you don't want to sign the papers for the surgery, I suggest that you leave the hospital." After hearing Dr. Wang's remarks, I became afraid of not going along with his decision. I didn't know of any other place that would take Junior, and besides,

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by this time his condition was too complicated to even contemplate another medical facility. Henry walked over to Dr. Wang and retrieved the permission papers he had presented to us. We signed them, and Junior was admitted the same day.

Early the next morning, the surgery was performed, and then he was taken to the recovery room. Dr. Wang came by to check on him and give the nurses instructions on how to care for the wound. He then turned and looked at Henry and me, smiling confidently. "Well, I see that Junior is doing fine. We need to run more lab tests on the lymph node we removed, and then hopefully I'll be able to tell you more about what is going on."

Later that evening, Henry left to work the graveyard shift while I stayed at the hospital. At around midnight, a nurse came into the room for a routine check of Junior's vital signs. When she discovered he had a fever and was bleeding uncontrollably from the wound, she immediately called the doctor, who ordered that Junior be given blood. Junior was transfused with packed red blood cells and platelets. I had assumed it was a complication of surgery, but it was much worse than that; for some unknown reason, his body was destroying the red blood cells and platelets as fast as he produced them.

Once the transfusion was complete, Junior was transferred to the Intensive Care Unit for further observation. I walked beside the stretcher as they rolled him down the hallway. He was placed in a private room in ICU, and then the nurse asked me to leave and wait in

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either his old room or the waiting room. Before I left the ICU, I instructed the nurse to give me a call if there was any change in Junior's condition. I got the phone number of the waiting room and left it at the nurses' station in ICU. The time dragged by, and I heard nothing. I became worried and called the nurses' station in the ICU to speak to the attending nurse. "How is my son, Henry, doing?" I asked her, barely holding it together.

"He's not my patient," the nurse replied, "but I heard that he has gotten worse. You need to come see him."

I was livid. *Why hadn't someone called me? I had left a number with a nurse and told her to call me if there were any change in Junior's condition!*

I hung up the phone, stormed out of the waiting room, and headed briskly down the long, freshly-waxed hallway. It reeked of pine and ammonia, and a fan had been placed there, presumably to help dry it. The wind blew against my face and body as I rushed to the ICU unit. By the time I got there, I was shaking with fear. *What condition would I find my son in?*

Finally I reached Junior's room and rushed inside to find two nurses standing over him. When they saw me, one began to clean up blood off the floor. I didn't need to ask, I knew the blood had come from Junior. I walked over to the bed and stood beside him. Ever so gently, I began to stroke his little forehead. He did not react. I don't think he even knew I was there. He had an IV in one arm that was transfusing blood and an oxygen mask covering his nose. I knew his condition was

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critical. My heart began to race and I felt my knees going weak. I had never felt so helpless.

"Where... where are the doctors?" I stammered, overtaken by panic. "Why aren't they here?" It was becoming too unbearable to see Junior like this.

I rushed out of his room and into the small passageway where the nurses sit to watch their patients. Insensibly, and engulfed with fear, I folded my arms tightly around my ribs and started walking around in a circle. I went faster and faster, unaware of what was happening around me. Another young mother stood in the doorway of her child's room, observing my actions. I saw her coming toward me, but in my state it seemed like she was moving in slow motion. As she grew closer, I could feel myself weakening. Instinctively, she grabbed a hold of my weary body and held me close. I shook uncontrollably in her arms, but no tears fell from my desolate eyes.

Next, I heard a voice say, "Has your son been baptized?" I glanced up to see where the masculine voice was coming from. It was a priest. He placed his arm around my shoulder and asked, "Do you want us to baptize him?" After getting no response from me, his deep, soothing voice boomed, "The Lord giveth and the Lord taketh away, blessed be the name of the Lord."

Of course, that was not the message I wanted to hear. "Please don't say that," I pleaded with him, "I know Junior is going to be fine."

The priest looked at me with doubt, as though he thought it was already too late. Instantaneously, my

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fears left me, and I dared to believe that Junior would pull through, and that he would be all right.

By daybreak, Junior was better. I stood beside him as he regained consciousness. He was alert enough to ask me to pick him up. When the doctor came in he delivered another surprise: the lump that was removed from under Junior's arm was not, as Dr. Wang believed, an enlarged lymph node, but merely fat.

Later that evening, I called my mother to discuss Junior's medical problems. Not wanting to worry her, I tried to speak normally. But as we discussed everything that had happened in the last twenty-four hours and the uncertainty of the future, I began to cry. She did her best to reassure me, and I did the same, telling her that Junior was much better and would be alright.

I knew Henry would be dropping off Laverne and Adam at Mom's house on his way to work, so before we hung up I asked her to tell Henry that Junior's condition had improved. But around 10:15 p.m., the nurse came to tell me that Henry was on the phone at the nurses' station. Mother had given him the message, but he was still worried.

"Do you want me to come and be with you and Junior while your mother has the kids? I could miss work tonight."

"No. You don't have to come tonight, because Junior is much better."

Reluctantly, Henry went on to work, but the next morning he showed up at the hospital with Laverne and Adam. I was so happy to see them; it made me more

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secure knowing that my family was there with me. I knew their visit would be short, as Henry had to go to work and Laverne had to go to school. Nonetheless, I was strengthened by their presence.

Their visit must have done wonders for Junior as well, because later that day he was discharged from the ICU and sent back to his regular room. A few hours later, a nurse came in, took him out of his bed, and placed him in a wheelchair. She then hooked his IV bag to a pole on the back of the wheelchair. I stood there, watching and wondering where she was taking him—probably to have more tests or x-rays. She opened the door to his room and began to push him down the hallway. I immediately followed behind.

Then my inner spirit compelled me to ask, "Where are you taking him?"

The nurse kindly looked at me and said, "I am taking him to have chemotherapy." Then, seeing the shocked look on my face, she asked, "No one told you that he has to have chemo?"

"No," I said in disbelief, "no one has mentioned a word to me about chemotherapy! His doctors told me that he doesn't have cancer, so why would he need chemo?"

The nurse opened the chart she was carrying in her arms and took a closer look at the room number and name. "Oh!" she exclaimed, her face turning beet red with embarrassment. "I am sorry. I have the wrong child. This chart goes to the child next door."

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She then turned the wheelchair around, pushed Junior back to his room, and assisted him back into his bed. I sat in the chair next to him, imagining how badly things could have gone if I had not been there to ask questions. After this mistake, I realized how very important it was for me to be with my child whenever he was hospitalized.

Chapter 10

Randall Enters The World

Four years later, on July 1, 1984, Henry, and I welcomed Randall, our fourth child and third son, into the world. We had fulfilled our dream of having a big family.

Randall was born at 12:40 p.m. He weighed seven pounds and one ounce, and was twenty-one inches long. Henry sat in the chair next to my hospital bed, his face radiating happiness and pride.

“All I need is two more boys and I’ll have my own basketball team!” Even though he adored Laverne, he saw in his sons a dream that he’d had since he was a child; it had always been his fantasy to become a famous basketball or football player, and now he hoped that they could live out that fantasy for him.

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I, on the other hand, only hoped they'd be successful at whatever path they took and live life on their own terms.

Once I was more alert, the nurse brought Randall to us. Henry and I cuddled him and showered him with love and adoration. Later on, the nurse returned to take him back to the nursery. A couple of days later, the doctor determined that we were both doing well enough to be discharged.

When we brought Randall home, Adam seemed confused; after all, he had been the youngest for four years, and now there was someone even smaller. He wasn't sure where he fit in, but after a while, he adjusted to Randall's presence and everything worked out just fine. It didn't matter to him that he was no longer the "baby". We made sure he understood that he would always have a special place on our laps, and in our hearts.

Chapter 11

A Tough Decision

During the 1984 and '85 school year, Junior turned five years old and we enrolled him in Head Start. His father and I were so proud to have our oldest son start school. We continually thanked God for blessing Junior and allowing him to live to see this day. That said,

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the thought of him leaving home and going to a place where I could not protect him terrified me. I made sure that the principal, the nurses, and his teachers knew about his blood disorder, which could cause severe nosebleeds. I also made it quite clear that if he became ill they were to contact one of us immediately.

It was March, 1985. Junior appeared to be doing better, but we knew he was still sick. On one of our visits to see Dr. Wang, he reminded us that it was time for Junior to have his spleen removed. It was the only way, he said, of correcting Junior's low platelet count.

"Once his subnormal spleen is removed, his blood count should shoot up and stay constant. Hopefully, this will resolve the problem." He continued by saying, "It shouldn't be any problem to remove the spleen. Many people have it done . . . especially football players."

There was nothing he could say to change how I felt. I was terrified of Junior having surgery again, especially after what had happened when the doctor's removed what they thought was a lymph node. I felt as though our backs were against the wall, yet I was also afraid of rejecting Dr. Wang's suggestion. Junior's medical condition wasn't going away. I believed that it didn't matter whether Henry and I agreed with their decision or not; the medical staff was ready to do the surgery anyway.

There were times I just wanted to pick my child up into my arms and flee the hospital with him. I was starting to believe that the physicians had taken over his body, as well as our rights to determine the best

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treatment for him. I had also started to believe that the physicians were making decisions about what to do, or not do, for my child, without considering his needs. This reminded me of a story of another parent who felt he had no control over his child's care.

A father, believing that they had neglected to properly care for his child, took members of the hospital staff hostage at gunpoint. Eventually, the man was shot and killed by the police. I do not believe what the man did was right, but I understand *why* he reacted in that way. He was trying to defend his rights and beliefs concerning the treatment of his child's medical condition. As a parent, you want what is best for your child. At the same time, you're at the mercy of the doctors; they have the training and the knowledge to at least try to figure out what the problem is--you don't. Yet, on the other hand, the doctors are human too. The human body is so complex; it is not always easy to determine what caused the problem in the first place. Oftentimes, the best a doctor can offer is an educated guess.

In the middle of March, Junior's spleen was removed, and as a result, he developed an infection in both ears. They had to place tubes in them to drain the infection. Even after he was released, we had to return to St. Jude's clinic approximately every two weeks in order to treat the infection. He was unable to attend school regularly or engage in activities that were normal for his age. There was some progress with his platelets, however, after the spleen was removed; and although they were still not at a normal level, they had stabilized enough to decrease the severe outbursts of

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bleeding. Still, I could not bring myself to be happy, because every time one problem seemed to be getting better, another would appear.

Throughout Junior's young life, he had been afflicted with severe blood infections. Because his body lacked the adequate number of infection-fighting white blood cells, he was extremely vulnerable to even the most common germs. The medical term for a low white blood count is leukopenia. Fever is often the first sign of a serious infection, and Henry and I were on guard at all times. We always hoped and prayed that the old Grand Torino would carry us through the rain, sleet, and snow as we traveled over the dangerous highways back and forth to the clinic. We learned to manage with very little money, often taking food and clothing from home for our stay at the hospital.

One beautiful sunny day in October, Henry decided to take the children out to the backyard to play ball. I prepared dinner for the family, then went into the living room to watch TV while the food was in the oven. After playing a couple of games, Henry came in and joined me on the couch. Every now and then, we looked out the kitchen window to check on the children. They were full of life-- jumping, running, and having a good time.

When dinner was ready, I called them indoors so they could clean up. After we finished eating, everyone gathered in the living room to watch television. Everything was fine, until suddenly, Junior started to shake all over. I checked his head, horrified to find that he was burning up with fever. Henry and I could not

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move fast enough as we gathered the children and their belongings and piled into the car. As we raced to the hospital in Memphis, sixty miles away, we gave no thought to the dangers of the icy roads.

During the long ride there, we kept talking to Junior, calling his name to keep him alert. Sometimes he would answer and sometime he would not. He sat up straight with his head resting against the rear seat of the car, as though he was asleep. We knew that he was getting weaker. By the time we had reached the clinic, it was obvious Junior wasn't doing well. Henry got out of the driver's side of the car and hurried around to the rear side where Junior was sitting. When Henry opened the car door, Junior almost fell to the ground, but his father caught him.

"Junior!" we called out several times, but there was no response. The only sound I could hear was my heart as it pulsed hard and quickly against my chest. Henry picked Junior up in his arms and ran as fast as he could into the hospital, the rest of us not far behind. As soon as we reached the large lobby area, people could tell by our faces that we had a real emergency. Everyone cleared the hallway as the doctors rushed to take Junior from Henry's arms and into a small emergency room filled with equipment.

The rest of us stayed out in the lobby while Henry remained by Junior's side. He prayed that God would grant Junior His grace once more. I saw nurses and hospital staff running into the room with different pieces of equipment. Each time I saw them enter the

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room with something, I prayed, believing that God was not going to take my oldest son.

Minutes later, Henry calmly walked out of the room, rubbing his bloodshot eyes. He told me that we had almost lost Junior. "They had to shock him twice to bring him back. He had actually died on the table," he said, replaying the whole ordeal. "The second shock was the good one that started his heart pumping again. Then the doctors kept working with him until his vitals became stable."

Even though we were scared, Henry somehow managed to make me and the kids laugh from time to time. Adam leaned up against me and uttered with such a childish voice, "Mom, is Junior going to die?"

"No, your brother will be fine." I had enough confidence to believe that God was going to give Junior the strength to fight his way through it all. I had Randall on my lap and Adam and Laverne sitting on either side of me. I reached over and put an arm around Adam, hugging him tight. "Your brother is strong; somehow he will make it."

A little while later, a doctor rolled Junior out of the emergency room on a stretcher. He was hooked up to oxygen and other equipment. We gathered our belongings, preparing to follow the nurses and doctor accompanying Junior. Before we left our seats, the doctor walked over to us and said, "If you had even stopped to put gas in the car, he would not have had a chance of surviving." With thankfulness in our hearts, we continued to gather our things, then followed the

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staff to the ICU. After arriving there, we waited in the lobby until we were informed of our son's condition.

The television was on, but Henry and I were both silently praying. Laverne and Adam sat patiently, wondering what could be going on with their brother. Randall was too young to realize what was happening.

Finally, we were informed that it was okay for Junior to have visitors. Henry and I would take turns going in to see him. He went first.

When he returned to our room, he told me, "The minute, I walked into Junior's room, I could feel God's presence. And in my spiritual mind, I could see an image standing right at the head of his bed; it appeared to be an angel. As I began to walk toward his bed, I had such a strange feeling. Then I heard a calm voice speak to my spirit, saying, *'Don't worry. Your son will be alright.'* At that precise moment, I felt God's spirit come over me. I walked over, took Junior's hands, and sighed with relief. I had been given reassurance that he would get up, and we would enjoy seeing him play and smile his beautiful smile again."

Three days later, while Junior was still in the Intensive Care Unit (ICU), a nurse came and opened the door to the waiting room where Henry and I sat. She looked sadly at us and said, "Henry Junior is not doing well, at all."

Right behind her, a doctor appeared. "If your son doesn't start to come around, or get any better by daylight, we will have to put him on a life support machine." It was already around four o'clock in the morning, but for some reason, Henry and I did not

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panic. We just calmly absorbed the words he was telling us without saying anything.

Shortly after the physician had left the room, another nurse opened the door and stuck her head in. She was so cheerful and had such a beautiful smile. "I brought you guys some good news. Henry Junior is doing better! What were you doing in here," she asked, "praying?"

Fortunately, he did not need to be put on life support. For now, God was his support. We knew God had extended Junior's life!

During visiting hours the next day, Henry and I went together to see Junior. When we walked into the room, we immediately noticed something different about him. Maybe it was because of all the commotion from the past few days, but we had not taken the time to examine him ourselves. Now we noticed that his fingers were an odd, bluish-black color. When Henry pulled the oxygen mask up a little off his face, we saw that the tip of his nose had also turned darker. We were not sure what was going on, but were so thankful to hear some good news for a change. We continued to believe that things were going to change from worse to better.

Later that afternoon, three young ministers came into the parents' waiting area and asked us if they could go into Junior's room to pray for him. "Yes," we told them, and his nurse escorted them to the room.

Over the following week, Junior continued to progress. He had started to show his beautiful smile again; it was as if the sun had come to shine light onto our otherwise dark world. He also began to talk with us,

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and to do something that he had always loved - eat. To watch him come through the wilderness, as he had just done, was so amazing.

A few days after the surgery, Junior seemed to be doing better. Henry and I were so relieved that we didn't dwell on the strange discoloration we had seen on his fingers and nose. Dr. Wang had come in regularly to check in on him. One day, after examining Junior, he turned solemnly to me and Henry and asked us to step out into the hall.

"Junior seems to be healing quite well from the surgery," he began, but behind the encouraging words was a grim tone. "But we have another problem. I'm sure you've noticed that his fingers and toes have that bluish-blackish color..." Henry and I nodded. "It looks like the infection in his ears has spread through his blood to other parts of his body, and it has affected his extremities." We nodded again, waiting for him to get to the point. "I'm sorry to tell you this, but it looks like we might have to amputate his fingers and toes."

Despite what we had just heard, Henry and I remained calm. I refused to accept any amputation was necessary, and this time, I refused to allow my faith to be shaken. I believed Junior's color would return and he would leave the hospital with every part of his body intact.

My intuition was right. A few days after Junior was moved from the ICU to his regular room, the color had started to come back into his skin.

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“If Junior starts to run a fever again, we’ll have to put him back on IV antibiotics,” Dr. Wang told us. “His life depends on it.”

The doctors continued to examine his fingers and toes each day, and they paid close attention to his nose. They were surprised and overjoyed to discover that the damaged parts of his body had started to lighten and peel; they were returning to normal. Fortunately, and partly due to my insistence, the doctors had stalled on making their decision to amputate. Now, after enduring so many close calls, Junior was dubbed the “boy with nine lives” by some of the hospital staff.

Not long after being moved to a regular room, we were thrilled to learn that Junior could come home with us.

During our wedding ceremony, Henry and I had stood before the preacher and God and vowed “to love and to cherish in prosperity and in adversity; in health and in sickness”. When we made that commitment, we could not have imagined how it would be tried, but now, with a sick child, we were beginning to get an idea.

Chapter 12

The Accident

In 1986, we bought a brand new Chrysler Fifth Avenue. Some people judged us because they thought

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we should have invested our money in a better home. The mobile home we lived in was ten years old and just didn't look as good as it once did. But Henry and I paid them no mind; we knew that having a reliable car with which to get Junior to the hospital was far more important.

Despite our optimism, this year would prove to be one of the family's lowest points. It was June, and I was seven and a half months pregnant with our fifth child. I was cleaning up after breakfast when the phone rang. The man on the other end said, "Hello, Gwen", and I immediately recognized the voice of Henry's manager at the plant. I could also hear his uneasy tone. "There was an explosion on the job, and Henry was in it. Gwen...he was seriously burned."

"How serious?" I asked.

"We don't really know yet, but he was taken by ambulance to the local hospital. It is important that you meet him there, right away."

I hung up the phone, trembling. I knew how bad these accidents could be. I stood there for a moment, forcing myself to take a few deep, slow breaths. After a couple of minutes, I had gathered enough strength to tell the children that their father was in an accident. Then I picked up the phone again to tell my next-door neighbor.

"Henry has been hurt on his job and I need to get to the hospital right away. Can you come along? I really could use some help with the children."

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She said she would, and I picked her up a few minutes later.

Once there, we went directly to the hospital's emergency area. I left the children in the waiting room with my neighbor and went into the room where they had placed Henry. He lay there on a bed with third degree burns over more than thirty percent of his body. He had been sedated to help him cope with the pain.

A day or two after the accident, Henry's burns became badly infected and he started to run a high fever. His condition was so severe that our family doctor suggested he be moved from the local hospital to one with a burn unit; it was in Memphis, nearly sixty miles away. I agreed. As Henry was being transported there by ambulance, I made the necessary arrangements to have someone look after the children.

The next day, I drove to Memphis to see him. As I entered his room, I did my best to hide my emotions so I wouldn't upset him. Still, as soon as I sat in the chair beside his, Henry could tell that I was distraught. I was seven-and-a-half months pregnant, taking care of our four children and driving back and forth to Memphis; I must have been a sight.

Concerned for me, Henry asked, "Are you okay?"

"I am fine."

He was not convinced and insisted that the nurse, who had come in to check his vitals, take my blood pressure as well. His nurse wrapped a blood pressure cuff around my arm and stared down at the

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gauge. From her expression it was immediately clear that my pressure was not normal.

"You should lie back for a while to rest, your pressure is a little high," she confirmed.

As instructed, I leaned backwards onto the recliner, and remained in that position for a few hours. When I felt able, I got up, kissed Henry goodbye, and walked slowly out to the car.

The traffic was heavy when I pulled out of the hospital parking lot that day. I began to feel nauseous, and the more I thought about the distance I had to drive home, the more my body began to weaken. I decided to pull over on the side of the road and relax until the feeling passed. After a few minutes, I began to feel a little better, but I was still a bit nauseous as I started the car and pulled out onto the highway.

As soon as I reached my mother's home in Wynne, Arkansas, I went inside and lay across her bed. Within minutes, I started vomiting uncontrollably. I felt as though I was dying. One of my sisters was there and heard me throwing up from the hallway. She came in to check on me, her eyes growing wide with fear when she saw how sick I was. She ran and got my mother, who told her to get me to the clinic. Our family doctor immediately took me into an examination room. "Gwen," he said after he had examined me. "What you are having is a nervous breakdown. You need to be admitted to the hospital for a few days to get some rest."

I was admitted immediately, and Mother came to stay with me. The following day, Henry received word that I was in the hospital near our home, and called to

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see how I was doing. Mother answered the phone in my room and assured him that I just needed rest and would be fine. It was the truth; a few days off my feet and I was feeling much better. The doctor sent me home, but told me I needed to take care of myself, as well as my family.

All I wanted was for Henry to be able to be there for the birth of our new baby. My hopes and prayers paid off; three weeks later, Henry was discharged from the hospital. It would appear things were beginning to return to normal, or at least as normal as it could be for our house.

But before long, faith and family would be tested again. It was a night toward the end of July, and the news was predicting a powerful storm heading in our direction. I had just finished cooking one of my family's favorite meals - spicy chicken wings--when the wind began to kick up outside. We carried the food into the living room and gathered around the TV to watch the Weather Channel while we ate. As if on cue, the rain began coming down in buckets, but when it started lightning we nervously turned off the television and huddled together. Every once in a while we would look out the window to check the progress of the storm. At one point, Henry got up and went into the kitchen to get more wings. On his way back to the living room, he stopped to look out the living room window. He saw the tall, but slender oak tree in our front yard bending to the ground. Then he looked across the street, just in time to see our neighbor's roof being blown off. What happened next was even more frightening: a telephone pole was lifted right out of the ground and hurled

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through their living room window. Then our mobile home began to rock.

“Holy cow!” Henry screamed, and broke into a run down the hallway. “Run!” he yelled back at us.

Two-year-old Randall stood in the middle of the floor, wondering what was going on. The other children followed behind their dad. As for me, running was not an option. At nearly nine months pregnant, I had to rock back and forth several time before I gained enough momentum to get off the couch. When I finally managed to stand, I made my way over to Randall, lifted him up, and took him to the bedroom, where my three other children had taken cover under the full-size bed. Henry had tried to get under the bed as well, but he was so big he could only get his head and shoulders under it. When I saw Henry having such a hard time, I knew I didn't stand a chance; I decided instead to sit on the floor with Randall in my lap. We sat at the foot of the bed until the storm had passed.

After it was over, we went back into the living room. We heard sirens coming closing and knew the storm had damaged many homes. We thanked God for the mercy He had shown us by not destroying ours and for sparing our family.

Suddenly Henry remembered the plate of chicken wings he had fixed earlier. He found his plate, but the wings weren't on it. He continued to look for the wings and found them, one by one, scattered throughout the living room and down the hallway. The kids and I teased him for being such a masculine-

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looking man, yet acting so scared when he saw the storm.

“Yeah, I ran!” Henry admitted. “I saw all of that action, I had to get away. God gave us five senses to use to protect ourselves, but He has proven that He has control over everything. It doesn’t matter how big of a man I am, it’s just natural to want to protect yourself from danger.”

The children listened patiently to their dad's excuses, and soon forgot about the terrible storm that had just passed over. As scary as it had seemed, we were able to find the humor in it all.

Chapter 13

Adrian Is Born

On August 12, 1986, I went into labor with our fifth child, Adrian. By the time we arrived at the hospital, the labor pains were so unbearable that I could hardly wait for her to be delivered. I still remember that my mother, who stood beside my bed, was very upset with the nurses and doctors. She didn’t think they were doing enough to ease my suffering.

“Gwen is my child, and if anything happens to her you won’t hear the end of me!” she barked at one of the doctors. “I’ll file a law suit on all of you!”

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An hour or so later, it was finally time for the baby to be delivered. After I gave birth, I was rolled back to my room to rest. Within minutes, Henry, who had stayed with the other children while I was in labor, hurried to my room to see if I was okay.

"What did you have," he asked anxiously, "a girl, or a boy?"

Mother knew Henry wanted another little boy, and she sat staring at my mouth, waiting to hear what I was going to say. Even though I'd heard the doctor say it was a little girl, I avoided Henry's question. This only aggravated him.

"I was under the influence of the oxygen," I declared. "Wait until the doctor comes in to tell us."

So that's what we did.

Finally, the doctor arrived, smiling broadly. "Congratulations, she weighed in at nine pounds and ten ounces, and is twenty-two inches long."

Without hesitation, Mother shouted, "Oh, my word! She is such a big baby!" She seemed to be enjoying the news way too much.

The doctor added, "She was born August 13, at 12:43 a.m."

It took a few moments, but Henry finally caught on that he had another girl.

"*She?*" he exclaimed, "What do you mean, she? Oh no, not a little girl! What can I do with girls? I need boys!" Then, realizing how irrational and insensitive he sounded, he paused and his entire demeanor changed.

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"Well...it's okay. I'll love her just the same. Laverne needs a little sister anyway." He smiled and asked the doctor, "When can we see her?"

"I'll have the nurse bring her soon," the doctor promised.

A few minutes later, Adrian was snuggled against my chest. Henry was quick to pick her up and cuddle her in his arms as he kissed her. It was obvious to Mother and me that Henry loved her as well as he did any of his three boys. Mother patiently waited for her turn, then took her new granddaughter in her arms. After a little while, she gave her back to me, and I cuddled her until the nurse came to bring her back to the nursery. Within a couple of days, Adrian and I were doing well enough to be released. Once again, we had been blessed with a beautiful child.

Chapter 14

Trials of Death

It was early October when Junior became gravely ill again. When he awoke one morning, his lymph nodes had enlarged dramatically. He also had a fever and there were painful ulcers in his mouth. The enlarged nodes around his neck and ears had literally changed his appearance. We wasted no time in rushing him to the hospital, and he was immediately admitted.

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While there, the doctors determined that he had developed a yeast infection, along with a persistent upper respiratory infection called the Epstein-Barr virus. This virus has been associated with infectious mononucleosis, as well as various types of cancer, including nasopharyngeal carcinoma, and Burkitt's lymphoma. Frequent medication was required for both the yeast infection and the respiratory infection. Since Junior no longer had a spleen, he continued on antibiotics and gamma globulin to help fight the infections. Junior would spend a month of his young life in the hospital before he was well enough to come home.

This episode prompted us to hire a young lawyer from Memphis, Tennessee, to file a lawsuit against the company responsible for putting Nur-soy, the contaminated formula, on the market. However, a few months later, the company provided proof that the Nur-soy formula was not responsible for Henry Junior's illness.

By January of 1987, Henry was still out of work, recovering from his injuries. The months without his salary had nearly depleted our savings, but we would soon have other worries to deal with. It was around this time that our second son, Adam, began to experience stomach problems. It was very important to me that he have breakfast every morning—whether at home or at school—in order to provide him with the necessary nutrients to sustain his frail body. He was not allowed too many sweets—a policy he highly objected to—because of his stomachaches.

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Despite this restriction on his diet, Adam returned each day with a large quantity of sweets. We weren't sure why or where he got them, but this went on for weeks.

To keep Adam from overindulging, Henry and the other children frequently helped him enjoy the treats. However, it soon got out of hand, and Henry and I asked Adam where he was getting them. Smiling, he did his best to convince us that he had received them from his teacher, but something just didn't click. The next morning, Henry took Adam to school so he could investigate.

"My wife and I have become concerned with all the treats Adam is bringing home, and we'd like to know if you've been giving them to him."

Somewhat puzzled, she asked, "What type of treats?"

"He has brought home two or three large candy bars, a variety of other candies, and packages of cakes."

She laughed and said, "Yes, I do give out treats almost every day, but not those types of treats."

Realizing Adam had tried to pull the wool over our eyes, Henry and the teacher laughed. Adam just sat in his seat, looking guilty, as if wondering what would happen next.

Henry thought for a minute, then said, "Well, if he isn't getting the treats from you, where did he get them?"

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Several of the children, including a sharp-witted little girl, heard Henry's question.

She raised her hand, as if to answer a question on a test, and shouted. "I know! I know!"

The teacher turned and asked her to come forward. "Did you say that you know where Adam has been getting that food?"

"Yes, ma'am," the little girl spoke proudly and boldly. "And I saw where he got it."

Adam's seat was further back from the teacher's desk, and because of the noise, he could barely hear what was being said. A little nervous about the conversation, he sat straight up in his chair and leaned forward, trying to read their lips.

"Where did he get the food?" Henry asked kindly.

"I saw him go to Jay's cubby box and get some candy bars from it," she explained.

The teacher and Henry kept glancing towards Adam, who was becoming quite anxious. He knew they were talking about him and could not figure out why it was taking them so long to say something to him. Finally, the teacher asked Adam to come forward. Sweat poured off his face as he nervously walked toward them.

"Adam," his teacher said, a bit sternly, "Have you been taking food out of Jay's box?"

"Yes, ma'am," Adam confessed. "I got it from Jay's cubby." Clearly, he knew he had been caught and saw no point in trying to deny anything.

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"I am glad that you didn't come up here and tell us a lie," Henry said with a note of pride in his voice. "That would have really upset me. You know that it was wrong to take Jay's food without asking him first. I won't discipline you for this, but you had better make me a promise that you will never do it again."

"Yes, sir, I promise," Adam assured him. After being excused, he turned and walked slowly back to his seat.

When Adam came home from school that evening, Henry was sitting in the living room, waiting. He called Adam over to stand before him.

"You hurt me today, Adam. I understand that you are only a child, and that when you see something sweet, it's tempting to you. In that little head of yours, you aren't thinking straight. Maybe when you feel your teeth sinking into that good, sweet candy bar, it makes you feel like you have gone to heaven." Henry smiled then, and Adam realized his father was teasing him. "But you did promise me that you wouldn't take anything else out of Jay's box," Henry reminded him.

"Yes, sir," Adam replied.

"Okay," Henry said, "Now you may go."

Adam left his father to go do his chores. The following morning, after getting dressed, Henry decided to drive his children to school. On the way, he stopped by the local grocery store, where he allowed them to pick out a few snacks. Adam looked around in the store and selected what he wanted, including a few sweets. Henry dropped them off at the entrance of the school,

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smiling as the kids got out of the car, then all turned and waved goodbye.

When school let out for the evening, Henry and I went to the bus stop to pick the children up. We noticed how Adam was not excited or playing as usual. Instead, when he got off the bus, he was walking straight, like a soldier, and looking ahead without a trace of a smile. He approached the car, opened the door, and sat in his seat, not saying a word to anybody.

Trying to swallow what we had just witnessed, Henry and I turned around and looked at him. We knew something had to be wrong.

Henry kindly asked, "What's wrong, Adam?"

"Nothing," Adam replied sullenly.

"Well, you're most certainly acting like something is wrong. Did you get into a fight or get whipped by your teacher?"

Adam did not say a word. Henry thought it would make it easier for Adam to answer specific questions. He asked again, this time a little more forcefully, "Which one of the two happened? You got into a fight, or you got a whipping?" Adam answered neither question, but remained in his seat with his mouth zipped shut. Now his father was growing very impatient. He asked once more, now demanding an answer. "Were you in a fight?"

"No sir," Adam replied.

"Did you get a whipping?"

"Yes, sir," Adam finally mumbled.

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“Who whipped you? Was it your teacher?”

“Yes, sir,” he answered, finally yielding to the truth. His face was expressionless.

“For what?” his father probed.

“I took Jay’s food.”

Henry instantly became upset, thinking that Adam’s teacher had whipped him for yesterday’s altercation. I thought the same. Henry turned to ask me, “Why would Adam’s teacher whip him after she heard him confess and promise that he would never take Jay’s food again?”

We both wondered why she would spank him for something that had been discussed the day before.

“Now I’m angry!” Henry shouted. “Why would your teacher whip you for something you did yesterday?”

“I don’t know,” Adam said with a dull expression on his face.

Hastily, Henry recalled that the teacher did not even know that anybody was taking food until he had gone to speak with her. The little girl in Adam’s class was the one who’d told on him. “Now she whips you!” Henry spoke with pure disgust in his voice. “Wait until we get home! I am going to give her a phone call and tell her a thing or two. Believe me, she will hear about this today!”

After we returned home, Henry called Adam’s teacher, and asked, “Why did you whip Adam after you

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heard him promise that he wouldn't bother with Jay's food again?"

"Well, Mr. McNutt, that's the problem. Adam did take Jay's food again today, after I had left the room. I left a student in charge to watch things, and she caught Adam taking Jay's food out of his cubby box.

"Jay was not at school today," she continued, "because he has the chicken pox. I found Jays food in Adam's backpack."

"How did you know what Jay had in his cubby?"

"I checked his cubby box before I left the room, therefore I knew exactly what he had in the box," she explained.

Henry's eyebrow lifted in surprise. He finished talking to Adam's teacher, hung up the phone, and turned to his son. "Adam, did you really go back into Jay's box again and get some food?"

Adam's eyes became very large, but he didn't answer right away. He just sat there, looking unblinkingly at his dad. Then he blurted out, "Yes, sir." He knew that his dad had finally uncovered the truth.

"Good for you, Adam! I'm glad that teacher whipped your little bottom. Ha! Ha! Ha!" He laughed mockingly. "You little rascal! You had no business sticking your hands back into Jay's cubby box again after you promised me that you wouldn't. She caught you red-handed. You were set up and fell right into their trap. Well, you brought all this on yourself, and after I went to the grocery store and bought you some snacks..." Henry shook his head.

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Adam kept his lips zipped, embarrassed by the fact that he had been caught and had gotten a spanking. "That's right! Don't you open your mouth to say a word, because you got what you deserved—a whipping! You little thief! You probably will get chicken pox from Jay because you ate the food from his box." Henry shook his head again. "I don't understand why Jay didn't come forward and tell the teacher on you in the first place. For a while, we thought your teacher was giving you those treats. Your mom and I even helped you eat it. You little scamp!"

Our other children, who had been watching and listening to the whole thing, burst out laughing. "Luckily me and your mother can't get the chicken pox again," Henry added.

Adam didn't say a word, but from the look on his face, I could tell that he was sorry for what he had done.

A couple of days later, Adam got the chicken pox. Junior and Laverne teased him about getting it from taking Jay's food.

Adam's defiance reminded me of a quote from the Bible: *Though he were a Son, yet learned he obedience by the things which he suffered* (Heb. 5:8). A few days later, Adam had the last laugh when his sisters and brothers got the chicken pox too.

We saw no evidence of it that day, but Adam would later become quite spiritual, and was even baptized in the church. Laverne and Junior, after seeing his spiritual transformation, would also become spiritually motivated. But although they too were

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baptized, I understood that they were still children and had to be taught God's words.

As the Apostle Paul said of his childhood, *"When I was a child, I spoke as a child; I understood as a child, I thought as a child, but when I became a man, I put away childish things."* (I Corinthians 13:11).

Foolishness is bound in the heart of a child: but the rod of correction shall drive it far from him (Proverbs 22:15).

Our family attended church often. Henry had made a complete turnaround from his childhood days; he became a member of the deacon board and served faithfully. Many times, we spoke with the pastor, lay members, friends, and relatives about Junior's ongoing illness. But it seemed as though God had given them a deaf ear, for they showed very little interest in the matter. We quickly noticed this fact, and understood that this was our burden and ours alone. We were young parents, but we were intelligent and had morals and we loved our children. We took care of our own responsibilities and put our faith in God to help us solve our problems.

In the midst of my struggles, I realized there were other children with problems too. Henry and I decided to reach out to the community and see what we could do to help. We organized a non-profit, after-school program called "Reaching Our Community Kids", or "ROCK". It was designed to motivate children who were slow in class by teaching them to have a positive attitude. The idea was to help them improve their grades and give them a second chance at an education.

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Once we developed the program, Henry decided it was also time to improve himself academically. He took classes through a reading program and in 1987 was named Student of the Year for conquering illiteracy. He was also recognized as the student who had read the most books, over and above his tutoring materials. His name was engraved on a plaque that was placed in an office at the Cross County Court House, along with testimonies by students and tutors. During his ceremony, Henry testified that he had realized the importance of learning to read after almost drinking denture cleaner. He thought it was Alka Seltzer because the boxes looked similar. He also told the audience that he became upset and depressed that he could not read and had considered taking his own life by poisoning himself. He went on to say, "My goal is to get a high school diploma. I am reading as much as I can. My children help me, as we read together."

I was so proud of my husband, and as the years progressed, our love for one another grew stronger. Although our joy and love continued, our trials never ended. Henry and I both knew that despite all of our bad days, our good days would outweigh them all.

By 1988, I was expecting our sixth child, Carl. He was the last "pea in the pod". On my seventh month checkup, my local doctor saw that my afterbirth was down too low. It appeared that it would come before the baby. He arranged for me to see a specialist in West Memphis, Arkansas, approximately forty miles from home. I went a couple of times, and the specialist noted that although the pregnancy was progressing, the afterbirth remained unchanged. Because it was getting

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close to my due date, he suggested that I have a cesarean section. I accepted his advice, but Henry and I became a little worried about the medical complications that could arise.

In the early morning of November 28, in my ninth month of pregnancy, I was awakened by contractions. I gradually sat up in bed while Henry lay asleep on the opposite side. The contractions came harder and harder. I yelled for Henry, and after seeing no reaction, I reached over and shook him. Henry slowly opened his eyes; then, realizing I was in labor, he swiftly got dressed and grabbed clothes for me to put on. Afterwards, he went into the children's bedroom and awakened them, telling them that it was urgent that he take Mama to the hospital in Memphis.

Henry called Mother, told her that I had gone into labor, and asked if she would come and be with the children. Although the pains were severe enough to take my breath away, I managed to get dressed.

After a little while, I stood up and crept to the living room. A contraction came, creating a stabbing pain that radiated down my spine. Henry hurriedly got everything together for the trip to the hospital, then helped me down the stairs of our home. I remember struggling just to walk to the car. I gripped the bottom of my stomach with my hands while clenching my thighs tightly together. Henry returned into the house to check on the children and left Laverne in charge to unlock the door for my mother when she got there.

Finally, after what seemed like hours, we left for Memphis. It was a long trip, but at least the highway

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was clear of traffic, allowing Henry to drive over the speed limit. Luckily, we made it to the hospital safely. Henry rushed out of the car and into the hospital, where he retrieved a wheelchair to carry me. The pains were so severe that I could not make it from the car into the chair. Someone who worked in the hospital saw me struggling and hurried outside to assist. Once inside, I was pushed directly into the delivery room. A specialist was called, and he rushed to the delivery room, expecting to perform a cesarean section. Henry stood in the hallway, waiting to hear the news. After all the drama it had taken to get to this point, I gave one little push and Carl was born.

"You have a little boy!" the doctor exclaimed. "Congratulations, Mrs. McNutt! You were lucky that a cesarean section wasn't needed."

The nurse proceeded to clean me up, then she and the doctor pushed me down the hall to my room. Shortly thereafter, Henry walked in with a big smile on his face. The specialist extended his hand. "Congratulations, Mr. McNutt, you have a son. Luckily your wife didn't need a Cesarean Section," he repeated. Henry stood there with a joyful look on his face that said, *"All is right with the world."* He stayed with me in my hospital room. An hour later, a nurse brought our new baby boy, Carl, to my room. As Henry cuddled him, he noted his small size.

"Gwen, look at this tiny fellow," he said as he held him up for me to see.

Later, the nurse came back into the room to take Carl back to the nursery.

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"How much does he weigh, and what is his length?" I asked curiously.

She gathered Carl into her arms. "Why do you ask? Is there something wrong?"

"No, it's just that my doctor never told us his weight or length and he looks sort of small to me."

The nurse smiled as she scooped up Carl in her arms and turned to walk out of the room. "Don't worry. I'm sure he's fine. He probably will grow to be as tall and as big as his dad."

Carl and I stayed in the hospital for twelve hours. Once the physicians saw that we were doing all right, we were discharged. Two weeks after we had returned home, I took Carl to a pediatrician in West Memphis to have an examination. His skin looked yellow. The doctor told me he had jaundice, and while she did not prescribe any medication, she did suggest that I keep him in the sunlight until his skin tone became normal. I did as she instructed, laying him on the living room couch, opening up the blinds, and letting the sunlight shine through the window on his small yellowish body. On his next appointment date, we went back to the clinic to visit his pediatrician. Carl's doctor was relieved to see his skin had returned to normal, and we were released to go home.

When Carl was seven months old, he was constantly agitated and had a poor appetite. We tried home remedies, thinking he was teething or had some other minor illness. The insurance company at Henry's job had changed. The new agency recommended our

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family to a different physician; one that was carried by that insurance. Therefore, we took him to see Dr. Jacob.

He examined Carl, and then told us, "Carl is wheezing and is heavily congested. It seems to be nothing more than a cold."

The new doctor prescribed medication to resolve the issue, and sent us home. Despite the medication, Carl continued to be restless, but when we took him back to the clinic, the doctor repeated the same information. Henry and I were very concerned about his frequent congestion and poor appetite. He would later develop a high temperature to accompany the congestion. One night, Carl seemed unusually restless and appeared to me to be very ill. The next morning, I drove Henry to work, then came home, got dressed and took Carl to the clinic. Dr. Jacob examined Carl, and I could tell from his expression that he too was concerned. He became even more alarmed when he did blood work and Carl did not react to the finger prick. Growing more and more anxious, I waited with Carl in the lobby for the results of the tests.

It was later that afternoon when Dr. Jacob called us back to the room. "Is anyone else in your family ill?"

"Yes, my oldest son," I replied.

"What's wrong with him?"

"There's something wrong with his blood, but I'm not quite sure what else."

Concerned, the doctor replied, "I'm not sure what is wrong with Carl either, but I am going to send him to a specialist in Little Rock. It is more than a hundred

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miles from Wynne, and you may have to make several visits there. I thought I would inform you of that, so you will be prepared." Then he asked, "Is Little Rock where your other child goes?"

"No, we take him to Memphis, to St. Jude."

"Well, then it probably would be better if you took Carl to Memphis, too. It is a shorter drive. Also, this way you won't have to take each child in separate directions. You don't need to take him today, tomorrow is fine. I'll call and talk to someone over there to inform them that you're coming."

Before we left the room, he gave me a paper with information on it, and told me to give it to someone in the admissions office when we arrived.

From there, we went home and I immediately began packing necessities for the trip. When Henry came home from work, I showed him the referral paper that the insurance company had sent, and told him that Dr. Jacob wanted Carl to be seen by a specialist in Memphis.

"What's wrong with him?" Henry asked.

"I don't know. That's why Dr. Jacob is sending us to St. Jude, to find out. I hope it's nothing serious."

"Do you have things ready for tomorrow, for the trip?"

"Yes, everything is packed and ready to go," I assured him.

"Well, I'm going with you. I'll call my job tomorrow morning and tell my boss that I need to take

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off from work. We have no idea of what type of news they're going to give us, and I want to be there."

"Well, I hope it's nothing that will scare us," I replied, trying to keep my voice steady.

The next day, November 28, 1989, Carl had his first birthday, and his first visit to the St. Jude Clinic. While we stood at the admission's desk, waiting to be checked in, a young lady asked us, "Why are you bringing your children here? First, you brought Henry Junior, and now you are bringing Carl!" She had a snobby tone that I really didn't appreciate. "Won't any other hospital take them?"

Henry was also stunned by her rudeness. "Where else can we take them? We don't know any other place to go except where our doctor sends us."

"Well, maybe you should try Le Bonheur Children's hospital," she added. "It's also a good hospital."

We never did find out why she made those remarks. After speaking with her, we were directed to the department of Hematology. Once there, the physicians ran many tests on Carl. They knew that something was wrong, but did not know exactly what. We only hoped that they would find the problem and help him get well. After the physicians finished examining Carl, they released us to go home. A new test of our faith had begun.

Chapter 15

Raccoon Eyes

Faith can be your friend or your enemy. When you put all your faith in God and all goes wrong, should you turn your back on it, or on Him? This is the temptation, but my faith in Him to make things better has never failed me, no matter how much I question it. The results are not always what I hope for, but the strength to carry any burden has always been found in the faith that God will see me through it.

It was the early part of 1989, and Adam was eight years old. He continually complained about stomachaches. Often he would lie around and sleep for hours. Henry and I thought perhaps he just needed a little more rest than the other children; after all, he was a growing boy. However, when we began to notice dark circles forming around his eyes, like a raccoon, I became very worried. It was time for a trip to the family doctor.

"I don't see anything wrong with him," Dr. Jacob said after examining him. "How does he act at home? Does he play very much?" Adam looked on, his eyes flicking from me to the doctor, and back again.

"Yes, he's very active at times," I replied, "But there are times when he sleeps a lot, especially in the afternoon when he should be doing his chores. Sometimes, I think he's just lazy and sleeps to get out of

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them.” I looked at Adam and smiled. “But what about the dark circles around his eyes. What causes that?”

“I don’t know. It may be something that nobody can explain,” Dr. Jacob said. He put his hand on Adam’s chin and slowly looked at his face and head. “It could be because his head and face are narrow. Maybe that’s what makes his eyes appear that way. I do not think it’s anything for you to worry about.” He seemed to ponder it for a few seconds before admitting, “I really don’t know the answer, but that’s just my opinion.”

This was not the answer I was looking for. Disappointed in his analysis, we went home.

When Henry arrived home from work, I told him about our visit to the clinic, including Dr. Jacob’s remark regarding Adam’s narrow head. Henry smiled, confident that Adam was just fine. I, on the other hand, remained concerned. I wondered if there was something more serious than a stomachache, or perhaps he was faking being sick in order to get out of doing his chores, or maybe to get more attention from Henry and me? I couldn’t figure it out, but I wasn’t satisfied with Dr. Jacob’s opinion.

I did not know where to turn or to whom, but after much thought, I decided on an optometrist. There was one close by, and I took Adam there without an appointment. My hope was that he could give me an answer about the dark circles around Adam’s eyes.

The optometrist looked at Adam and asked, “What is the problem?”

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“Adam has dark circles around his eyes, and I want to know why they are there.”

He held Adam’s chin, looked at his eyes, then turned to me and asked, “Does he have a problem seeing?”

“I don’t know!” I snapped, and knew my anxiety was getting the better of me. “He has never complained about his eyes, only his stomach.” I turned to Adam. “Do you have a problem seeing the writing on the board at school or when doing your homework?”

He bowed his head down and answered, “Sometimes I can’t see the writing on the board that well.”

The optometrist stood looking at Adam for a few seconds and said, “His vision doesn’t have anything to do with the dark circles around his eyes. However, you need to get a doctor’s appointment and bring him back for an eye examination.”

When we returned for the follow-up, the optometrist said that Adam’s vision was poor and prescribed glasses.

I was pleased that I had gotten help for Adam’s vision, but we still hadn’t gotten any answers about his frequent stomachaches and the dark circles around his eyes.

In August of 1989, Randall started kindergarten. Each day, he, Adam, and Laverne walked the few blocks from our home to the bus stop, and then reversed the trip on the way home. Late one evening, Adam walked into the house and complained that he was not feeling

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well. When I placed the back of my hand on his forehead, his skin felt warm to the touch. I retrieved a thermometer and checked his temperature, and sure enough, he had a fever. I thought he might have a virus, or some other minor illness. I kept him home from school for a week and treated him with over-the-counter medicine. But when he was still sick the following week, I took him back to Dr. Jacob. He examined Adam, said it was nothing more than a cold or the flu, and prescribed medication for him. I kept Adam home for another week and he appeared to progress well. After two weeks, it was time to go back to school.

In September of 1989, Henry's family moved from their farm outside of Palestine, Arkansas and into the lovely new home his parents had purchased in Forrest City, about twenty-miles from Wynne.

Around this time, we bought a used pick-up truck, as well as a used van, to accommodate our large family. Henry often drove the truck to work, leaving me with the van in case of an emergency. One evening, we took the truck to visit his mother and siblings that still lived at home. She was very happy to see us and our children, and we were thrilled to see that she now had a more comfortable place to live.

The time flew, and soon it was time to go home. Henry's mother's walked us out to the truck and Adam, Junior, Laverne, and Randall climbed into the back. Adam stood up, and as we got ready to leave, Henry's mother slammed the door shut, not realizing his hand was inside the doorframe. Adam screamed, and we immediately examined his hand to see how bad it was.

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It was swelling right before our eyes and we knew he needed to see a doctor right away. We sped to the local clinic, where x-rays revealed that several bones in his wrist were cracked. He'd have to wear a cast for several weeks. It seemed awful that night, but it would later seem minor in comparison to what was to come.

Thursday, March 20, 1990, began like every other day, with Adam, Junior, Randall, and Laverne heading off to meet the school bus. They were late coming home that afternoon, and while I was a little concerned, I figured they were just horsing around on their way home. I shook off the feeling and continued preparing dinner and taking care of little Carl and Adrian.

When they finally made it home, I was happy to see them, but also a little upset. I chastised them about coming home late, and that's when Laverne said, "Adam got tired and couldn't walk. He sat on the edge of the road to rest. After he was rested," she continued, "he was still too weak to carry his books. Junior and I had to carry them home for him." While Laverne explained, Adam lay down on the couch.

"Adam, what's wrong? Are you hungry?" I asked.

"Yes, ma'am," he replied.

"Maybe that's why you are tired and weak. Go wash your hands and sit down at the table. Maybe after you eat you will feel better."

Adam and the other children washed their hands and returned to the dinner table to eat. When Adam remained lethargic even after the meal, I became

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extremely concerned. Once again, I took him back to Dr. Jacob, and again, Dr. Jacob found nothing wrong with Adam.

Luckily, around the beginning of April, there were changes to Henry's health insurance plan, one of which required the children to see a new pediatrician. Dr. Curtis Patton was located in Forrest City, the same city where Henry's mother now lived.

The following week, our daughter Adrian had a bad cold. I helped her dress, and then we headed off to the doctor. As Henry and I were getting out of the van, nine-year-old Adam looked at me and said, "Mamma, if I don't see a doctor, I ain't gonna live."

We left the other children in the van while we went inside with Adrian, but Adam's words weighed heavily on our minds. While Dr. Patton was examining Adrian, Henry asked him if he could see Adam too. He explained about Adam's complaints about his stomach, and what he had just said about needing to see a doctor.

"Where is he?" the doctor asked.

"He is out in the van," Henry replied.

"Well, bring him in and I'll take a look."

Henry went out to the van and got Adam. Dr. Patton, who was aware that Henry Junior and Carl were patients at St. Jude, took one look at him and ordered blood to be drawn. The blood work revealed that his hemoglobin count was only three. This was extremely low; in fact, it was life threatening. Adam's statement about needing to see a doctor had been terrifyingly accurate.

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"His hemoglobin should be at least eleven or more," Dr. Patton explained. He told us that Adam could go into shock, or even die, and needed to get to a hospital immediately. The doctor then asked if we wanted to go by ambulance, but we said we'd take Adam in our own vehicle. We rushed him to St. Jude, where he received a blood transfusion. Afterward, the doctor there scheduled a follow-up appointment a few days later.

When we returned for his appointment, we brought Adam to the Immunology ward. We were very familiar with this part of the clinic since it was where we always took Junior. The doctors ran several tests, then Henry, the kids, and I stood in the hall and waited for Adam's diagnosis.

Sometime later, a tall, handsome doctor with salt and pepper hair walked up to us and extended his hand. "Hello, Mr. and Mrs. McNutt," he said in accented English, "It's nice to meet you. I am Dr. Raul Ribeiro." He looked down at Adam, who had a Band-Aid on his arm. "And this must be Adam." He began to play with our son, trying to make him feel comfortable. It worked, too, because despite all he had been through, Adam began to laugh.

We were soon joined by Dr. Wang as well. "I see you've already met Dr. Ribeiro. Your sons will be seeing him from now on, here in the Immunology clinic."

Dr. Wang then explained that he had taken another position in the hospital. I remembered feeling confused and frightened about changing doctors during such a critical time in our boys' lives. By that time, Dr.

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Wang had been Junior's physician for several years. Would Dr. Ribeiro be as good as Dr. Wang? Was it wise to change doctors, given Junior's illness? What could I do about it; did I even have a choice in the matter?

A nurse watched the children while Dr. Ribeiro took us into another room. He explained how ill Adam was and the importance of keeping an eye on his hemoglobin count. Dr. Ribeiro then gave us another appointment for the following month.

On the way home, we were glad that we had taken Adam to the clinic. We only hoped and prayed that he would not need more blood transfusions.

Late one evening, Adam and our other children were outside playing when he accidentally stepped on a board that had a nail in it. The nail penetrated his foot and went through the top layer of skin. He barely bled, but Henry and I immediately took him to the local hospital anyway.

We had to stop at the admission's desk in the emergency room in order to have him admitted. The receptionist asked us a few questions, and we told her that Adam was a patient of St. Jude. After he was diagnosed and prescribed medication, the doctor told us to take him back there for a follow up. As soon as we got home, Henry called the doctor at St. Jude and told him about the incident, and it was decided that although he had no fever and was doing well, we would take him to the clinic the following day.

The physicians at St. Jude examined Adam, then told us to take him to Le Bonheur Children's Hospital, just a few miles away. The doctors at Bonheur found

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that he had Cellulitis on his foot due to the puncture. Cellulitis is a skin infection caused by bacteria. Normally, your skin helps protect you from infection, but if you have a cut, sore, or insect bite, the bacteria can get into the skin and spread to deeper tissues. If left untreated, the infection can spread to the blood or lymph nodes, which can be deadly. The doctors admitted him so they could administer antibiotics and watch him around the clock. Fortunately, the medication worked and within a few days, Adam was released from the hospital.

Chapter 16

All Three At Once

On August 27, 1990, Dr. Ribeiro saw all three boys - Adam, Henry Junior, and Carl. During this time, Adam was not on any medication, and had no fever, diarrhea, or bleeding. His hemoglobin level was up to 8.5g/dl. We had his blood count checked regularly, and if needed, he received a blood transfusion. His white blood count was 1700/cu. mm and his platelet count was 16, 000/cu. mm. The lab results showed that his antibodies to both Hemophilia influenza and Pneumococcus were very low. He was immunized with the Pneumovax, and would repeat his Pneumococcus Titers on his next visit. Before we left the hospital, Dr.

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Ribeiro gave us a “doctor’s note” so Adam could be tutored at home instead of going to school.

Shortly after their visit to Dr. Ribeiro, Henry Junior developed a nasty cough, which got worse at night. Both his ears developed a foul-smelling, green drainage. The plus side is that he had no problem with bleeding, diarrhea, or fever.

Carl had been doing well prior to this visit to the doctor, with only an occasional episode of mild diarrhea. He had even gained a couple of pounds over the past few months. However, although everything appeared normal, his last examination had showed that he was prone to febrile seizures. His laboratory tests included a white blood count of 7100/cu. mm, with an Absolute Neutrophil Count of more than 3,000/cm. mm. He continued taking his regimen of Amoxicillin, multivitamins and Bicitra and would return to St. Jude the following month with his brothers.

Adam, Henry Junior, and Carl continued to get examinations and transfusions as needed. On one visit, their physician saw that Carl’s white blood count was well below normal, and decided that he should wear a helmet to protect him from hitting his head and possibly cause brain damage. Meanwhile, Henry and I continued to pray, asking God to turn things around and make things better for our sons. Through it all, our trials lingered, but our faith never wavered.

In June of 1991, we decided we needed a family vacation. Henry requested a week off from work so we could head to Chattanooga, Tennessee and visit Look Out Mountain. The day before we planned to leave,

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Henry Junior, Adam, and Randall were outside with their father while he tilled a few rows in the vegetable garden. After a while, Junior came into the house, complaining of a headache. I thought perhaps he had gotten overheated and just needed to come in and cool off for a bit. He sat down on the living room floor in front of the air conditioner and I looked in on him every few minutes to make sure he was all right. He seemed comfortable enough, but I noticed that a knot had formed above his left eye. I immediately told Henry, who turned off the garden tiller and rushed to Junior's side. As he examined the bump, he asked, "Is something hurting you?"

"Yes, sir. My head is hurting," Junior said rather weakly.

I walked over to them and crouched down to get a better look. "How did the knot get there?" I asked Junior, "Did you bump yourself?"

"No, ma'am." He put his hand to his head, rubbed it, and offered me a small smile. "I don't know how it got there. My head just started to hurt while I was outside. That's why I came in."

"I think we better call St. Jude," Henry said, clearly concerned. "It could be something serious."

I nodded and Henry reached for the phone. As soon as the doctor heard about the bump he told us to bring Junior in. We immediately gathered the children and the things we would need for the trip and set out for Memphis.

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Upon arriving at the clinic, we followed the same routine: the drawing of blood, then an examination. The doctor observed the knot that had formed on Junior's forehead and we told him about the headaches. Like us, Dr. Ribeiro didn't understand what was happening; all he could do was prescribe medication and hope it got better. Henry and I considered cancelling the trip to Chattanooga, but Junior wouldn't hear of it. Thinking the trip might help lift his spirits, we left the next day as planned.

We arrived in Chattanooga around noon and checked into a hotel. As a precaution, we had brought along a wheelchair in case Junior became too weak to walk. For a while, he seemed to have forgotten about the pain. I felt good as I watched him get on the incline railroad train so we could ride to the top of Look Out Mountain and tour Point Park, a Civil War battlefield. Then, as we were getting back on the train after the tour, Junior told us that his vision was blurry and he needed to rest.

We went to a restaurant for dinner, then back to our hotel. By that time, Henry and I had already decided we would leave the next day. When we got home Saturday afternoon, Junior still had pain and his vision was blurry, despite taking his medicine.

Sunday morning, we woke and got dressed for church. Junior needed dark glasses to shield his eyes from the ceiling light and the sunlight. We were aware that the church had a rule against wearing sunglasses inside. We were also aware of a few faultfinders within the congregation. Thinking people would be upset with

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him, Junior was nervous about wearing the dark glasses. As soon as we got to church, he called out to an Elder Deacon to explain so he wouldn't be embarrassed later. The Deacon came over to where we were sitting and Junior explained why he was wearing the dark glasses. The deacon understood his problem, and luckily, nobody else complained.

That day, while I sat in my seat during the church service, I silently prayed that God would work a miracle and heal my boys, or that He would help the physicians find the cause of their medical problems so they could heal them.

When the church service ended, we went directly home. Junior lay on the couch to rest, and Adam sat on the floor beside the couch, watching television. Later, that evening Junior's pains became excruciating, causing him to yell out.

"I am hurting," he cried, "and I barely can see!"

Once again, we sped the sixty miles to St. Jude.

As usual, we went directly to the lab to have his blood work done. But this time, when nurse stuck his finger to smear blood on the microscope slide, it was so clotted that it rolled off and onto the table! The nurse ran to get a doctor.

As soon as the doctor saw Junior and the blood sample, he told the nurse to rush him to the intensive care unit. By this time, Junior was screaming in agony and his body was swelling at a rapid rate. The doctor called other doctors into the room. They looked at him and examined him, but no one could figure out what

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was wrong. Henry could not bear seeing his son in so much pain and left the room. Suddenly, Junior began to complain that there was no one in the room with him. At this point, he was completely blind and surrounded by darkness. He could not see anyone.

Terrified, he cried out, "Am I alive? Mamma! Mamma!"

Feeling scared and helpless myself, I ran to his side. "I'm right here, darling! I won't leave you!"

I held and caressed his hand, then kissed his forehead to assure him that I was there and would do everything in my power to protect him.

But he just kept writhing in agony and crying, "I can't see anybody! Where is everybody?"

It was so awful that one of the doctors left the room and stood out in the ICU hallway with Henry. I knew the doctor was trying to think of a solution, but I rushed to the door and shouted, "Do something to help my son! I know there must be something you can do!" When he didn't answer, I walked right up to him, looked straight into his eyes and pleaded, "Please do something to help him! I am afraid he will die!"

One of the other doctors turned to me and said, "We are trying to help him! Right now there is nothing we can do!"

"Then get out your medical book," I snapped angrily, "and study!"

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Now the doctor looked angry as well, or maybe it was just frustrated. "Look! There is nothing to study; we have nothing to go on!"

A few minutes later, medical workers came with a machine that would draw Junior's blood through a tube, thin it, and then put it back into a different part of his body. But when they hooked him to the machine, his blood was too thick to pass through the tube.

A nurse saw us in the hallway and asked about Junior's condition. When they told her what was happening and that they had no idea what to do, she swiftly rushed into the room. She looked at Henry and me as she pulled out a large syringe and said, "Pray and keep your fingers crossed! I hope this will work!"

Henry and I looked on in horror as she inserted the needle into a vein in Junior's foot. Then she pulled back on the syringe, trying to expel the blood from the vein in his foot. Slowly, jelled blood came out of the vein and filled the syringe. She repeatedly emptied the syringe of the jelled blood from his foot, while at the same time an aid pumped fresh blood into his arm. This routine was repeated until his blood began to thin. I'm not sure how she knew to do this, but this nurse was truly Junior's guardian angel. After a two-week hospital stay, Junior was discharged; however, he wasn't home for very long. When we returned to the clinic a few days later to have his blood rechecked, it was still not completely normal. They immediately admitted him back into the hospital, and this time, his blood was thin enough to be placed on the machine. It removed his blood, thinned it, and then placed it back into his vein.

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After a couple more times on the machine, his blood returned to normal.

A week after that, we had an appointment to take Junior back to the optometrist to have his eyes examined. The optometrist discovered that after the episode of his hyper-coagulation (blood clotting), Junior had begun to hemorrhage slightly behind his eyes. Fortunately, after several more visits, the doctor said it had stopped.

As Junior had developed various medical conditions that required frequent IV medications, the doctors felt a Hickman Line (central venous catheter) was the most efficient way to treat him. Henry and I were horrified that our son had to have this catheter in his chest, but if it would help him we had no choice but to consent. Later that year, Dr. Ribeiro went on sabbatical and Dr. Konz, who had worked closely with him, took over our boys' frequent visits. In my opinion, she had a rather snobbish attitude, and paid very little attention to their medical problems. When, for example, we told her about the greenish, foul-smelling discharge coming from Junior's ears, or about the blood leaking from the Hickman Line, she made no effort to look into the problem. I became very upset about her nonchalant attitude. I knew the greenish discharge and the foul odor could be a sign of a serious infection, but she refused to listen. After a few months, I complained to the hospital board and asked that she be removed from assisting my boys.

Luckily, Dr. Ribeiro had just returned from his sabbatical and resumed care of our boys. He thoroughly

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researched Adam's medical problems and, given his chronically low white blood count, decided he should have blood transfusions on a regular basis. He also suggested that Adam get started on Granulocyte colony-stimulating factor, or G-CSF. Also known as colony-stimulating factor 3 (CSF 3), G-CSF is a glycoprotein that stimulates the bone marrow to produce granulocytes and stem cells, then releases them into the bloodstream. The doses were administered with a syringe. The needle was injected into a layer of the skin, not into a vein. G-CSF has been successful in raising white cell count in other diseases, yet even after treatment, Adam's absolute neutrophil counts (ANC) were still lower than normal. His platelets were also low; however, he was not transfused with platelets that day. Instead, Dr. Ribeiro asked a question that threw me for a loop.

"Have you considered letting Adam get a bone marrow transplant?"

"No," I quickly answered, "I haven't, and I don't think that would be a good option for him. I am afraid his body couldn't take the trauma."

After I had calmed down, however, I asked Dr. Ribeiro to tell me more about the procedure, as Henry and I were completely uneducated on the subject. But before he could explain, three female doctors from the bone marrow team entered the room. I didn't know where they were from, but each spoke in heavily accented English as they discussed the severity of Adam's illness.

"He is getting a lot of blood transfusions," remarked one, her piercing green eyes showing no hint

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of emotion. "If he continues to receive an excess of iron, which found in the red blood cells, other problems may arise."

Another doctor chimed in, using medical lingo that I had no hope of understanding. "Excessive iron deposits overwhelm the storage limit of the Reticuloendothelial system and cause toxic overflows of iron into the liver, heart, pancreas, and other organs. If you decide later to let him have the transplant, he may not respond to the treatment, and could die."

My heart froze when I heard the words, "and could die". I wanted to gather my boys from the waiting room and escape, never to return to this building of horror. Since I knew this was not an option, I simply returned to my boys, forcing a smile so they would not know how serious things were. Somehow I managed to appear calm as I walked over to a chair and sat down.

"What's wrong, Mrs. McNutt? You seem upset about something."

I glanced up and saw a nurse standing there. "Yes, I am," I answered, my voice breaking. "Dr. Ribeiro and those women on the bone marrow team told me that Adam needs a bone marrow transplant." I wiped the tears from my face. "I don't understand why they want to give him a transplant when they don't even know what's wrong!" As I heard the words coming from my mouth, I felt myself growing angrier. "The fact is, I'm not sure if they know what's wrong with Adam, or any of my boys. It seems as though everything is based upon what they believe or think, not what they know. No, I can't let them do it!" I cried, "I am not going to let him

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have it!" With that, I gathered my boys and left the clinic.

We arrived home and waited for Henry to come in from work. I told him how they had recommended a bone marrow transplant and how I had gotten so upset at the hospital. But Henry remained calm and told me not to worry.

On the next visit to the clinic, Henry went with us. Dr. Ribeiro repeated what he had already told me about Adam's condition, then he said, "We do not know for sure what disease Adam has, and I don't think he should have a bone marrow transplant until we do."

I exhaled, relieved that he had changed his mind about the procedure. Dr. Ribeiro paused for a moment, then he said, "I have spoken with a specialist at Rockefeller University in New York City, and she is offering to evaluate your boys. If we could send all of you--all expenses paid--would you go?"

Henry thought for a couple of seconds, then said, "Yes, I guess, but would we have to take a plane?"

"Yes," Dr. Ribeiro replied. "A bus or car would take too long."

Of course, we agreed to go. We needed to know what terrible disease was attacking our boys and making them so ill.

It was very late when we trudged out of the hospital and headed home. On the way, Henry spoke with the boys about the upcoming trip to New York City and, as usual, they hung on his every word. Henry had always been their counselor, talking to the children

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about life, death, the importance of being a Christian and living a moral and respectable life. They had heard about Heaven a lot; perhaps that's why their earthly problems did not seem to bother them very much. Adam even told us that he sometimes visualized Heaven in his mind, calling it "a city of pure gold". He often thought about how beautiful Heaven was and how wonderful it would be to live there, to walk those streets paved with gold.

Hearing him talk this way, it reminded me of the passage from Scripture: *"And the building of the wall of it was of jasper: and the city was pure gold, like unto clear glass."* (Rev. 21: 18)

With his face lit like a glistening star, Adam said, "I wonder what it really looks like. I want to be a Christian, so I can see it. It's got to be beautiful!"

There was a bright, gleaming moon that night, and shone down upon the highway as if to light our way. Adam looked out the car window and up into the dark, star-filled skies. His smile radiant, he bounced playfully in his seat as he pondered the notion of the golden city.

On the boys' next appointment, Doctor Ribeiro asked us to bring our daughters along as well. He wanted to run DNA testing to determine whether they were a match to Adam's bone marrow. Sure enough, the test revealed that Laverne was a perfect match.

Dr. Ribeiro smiled as he delivered the news. "It's significant when the patient's donor is a relative, especially a close relative like a sister or brother. I have confidence that everything will be fine with Adam."

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After that, Henry and I began to believe that a bone marrow transplant would work. Then another disturbing thought crossed my mind. "But what about all the blood transfusions Adam has had? Doesn't that mean there's a major risk of him not surviving the treatments?"

"He's only had red blood, not platelet," replied Dr. Ribeiro. "And he seems to be strong. I think he will do all right."

He then pulled out a paper he had gotten from France; it listed the names of people who had survived the transplant, along with a few that had not. "More than seventy percent of the patients survived, so Adam has a great chance."

Despite his reassurances, I was still terribly afraid. Seventy-percent of people may have survived, but all I could think about was the thirty percent that didn't.

Dr. Ribeiro explained that we should be prepared to be in New York for a week. "Dr. Auerbach and her staff at Rockefeller University will examine the boys, run some tests, and try to find out what is going on with them. I hope that she will be able to give you enough information to make you comfortable about your decision." We nodded, and Dr. Ribeiro scheduled an appointment for us after the trip.

We were assigned a social worker, Chris Sinnock, who gave us the information about the trip. We were booked on a flight that Sunday at 10 a.m. Next, she gave us the information that we needed to give Dr. Auerbach once we arrived at Rockefeller University. It seemed like

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hours later when we finally left to go home, our heads swimming with details about travel plans and medical tests.

My faith in God never wavered during all of this. However, my faith in doctors had yet to be established. Our boys had been through so much already, and at such a young age. What more lay ahead for them? Like any parents, we could not stand to see our children suffer, and it felt even worse because we didn't know what was causing it. Now, as we prepared to leave for New York, we could only pray that this trip would bring us some answers.

A few days before Christmas, we dropped Laverne and Adrian off at my mother's. After a tearful goodbye, Henry, the boys, and I boarded the flight from Memphis to New York. LaGuardia Airport was packed with holiday travelers, but after a long wait, we grabbed out luggage and hailed a taxi to take us to Rockefeller University in Manhattan. When we got there, two people were waiting for us right outside the entrance, and they took us to meet Dr. Arleen Auerbach. Everyone was so kind and helpful, although we had to struggle a bit to understand Dr. Auerbach's staff, for they all had thick foreign accents.

After the introductions, we were escorted to our home for the week: two sparsely decorated but comfortable rooms next door to each other; each had two double beds. We took a few minutes to settle in, and then a staff member came to gather information about our family history. We were asked questions about our parents and grandparents, and whether anyone in our

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family was of mixed race. There were also several peculiar questions, like, "Are you and Henry from the same town? Are your parents from the same town? Are you and Henry related to each other in any other way, such as sister and brother or any other close relations?" Our answers to all of her questions were the same, stunned, "No." We could not believe they had even considered the possibility that Henry and I were related.

We were exhausted by the time we finally we returned to our rooms. Henry and the three older boys slept in one room, and Carl and I shared the room next door. Although there were two beds in the room, I slept with Carl. The building, like the city, was so huge and unfamiliar, and I figured he shouldn't have to sleep alone too.

For the next week, we followed a routine that felt eerily familiar to St. Jude. After we ate breakfast and got dressed, we would go to Dr. Auerbach's office so she could examine the boys. After each visit, she would send us to other labs throughout the city for further tests. We took enough cabs that week to last a lifetime! Each lab had a different specialty: one place would collect blood and flesh from each boy's thigh; another would do bone marrow biopsies. The tests were not always the same, but even with anesthesia, they were often painful. Hearing our boys cry out for help was like being stabbed in the heart. Henry and I wanted desperately to ask the technicians to stop, but we knew the tests were necessary if we were ever going to get any answers.

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Carl was only three years old, so he cried the most. Henry held onto him, whenever he was permitted. Carl would be crying out, "Not me! Not me, Daddy!", and all Henry could do was stand beside him with tears in his eyes and hope in his heart. Like me, Henry felt an overwhelming helplessness. It was all he could do to stand by and watch as his boys suffered the pain and fear, especially from the bone marrow aspirations. Several days later, once all of the medical tests had been completed, we walked the cold winter streets of Manhattan. The streets were decorated for the holidays, and we saw many beautiful things that filled our hearts with joy and happiness. This was the best medicine to help take our minds off the illnesses that brought us here in the first place. The streets were crowded with people, - some literally dancing - enjoying the spirit of Christmas.

When we arrived back at the hospital later that day, we were surprised to learn that a news reporter from Washington, D.C. had driven up to the University to interview us.

"Unfortunately, they missed you," the hospital staffer said.

We never knew who told the reporter about us, or why he had chosen that day to come up.

A nurse and several other workers at the University managed to get us into the studio where they filmed *The Cosby Show*. We sat in the Green Room, watching as they cast the episode. It was such an incredible treat for our boys to meet and talk with some of the stars of the show.

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Finally, the week was drawing to a close. As we prepared to leave Rockefeller University, Dr. Auerbach called Henry and me in for a conference. She explained that all of the boys had a disease called "Fanconi Anemia". In addition, Carl and Henry Junior carried a disease called "Wiskott- Aldrich". She then explained that a bone marrow transplant was indeed the only cure. Adam would be the first to have the procedure.

Fanconi anemia (FA) is named for a Swiss pediatrician, Guido Fanconi. In 1927, Dr. Fanconi published his clinical observations on brothers who had inherited various abnormal physical conditions, and who also experienced bone marrow failure. These children suffered severe life-threatening aplastic anemia. Their blood system could not successfully combat infection, fatigue or spontaneous hemorrhage or bleeding. FA is one of several deadly inherited anemias.

Both parents must be carriers of a recessive FA gene for their child to be born with this disorder. If both parents carry this gene, the chances are one in four that any of their children will inherit the disease. Scientists call this "pattern of inheritance".

FA patients may have a variety of noticeable birth defects, ranging from minor to serious. These defects may affect every major system of the body. Other FA patients are free from any visible disorder-other than ultimate bone marrow failure. They also experience a high incidence of leukemia, and have a much higher incidence of cancer than the general population (10% -15%). The chromosomes in the cells of FA patients, when studied in the lab, break and rearrange easily, Scientists do not yet

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understand this basic defect in those with FA but can use it as a diagnostic test for the disease.

Fanconi Anemia Handbook, part I, page 3; Lynn and Dave Frohnmayer.

Wiskott - Aldrich syndrome - (WAS) is named after Alfred Wiskott (1898- 1978), a German Pediatrician, and Robert Anderson Aldrich (born 1917), an American physician. WAS is a hereditary, sex-linked, recessive disorder characterized by chronic eczema, recurring infections, and a decrease in the numbers of white blood cells and platelets.

WAS is an x-linked recessive disorder that only affects males. This disorder is comprised of three different factors. First, there is a deficiency in both the B-lymphocytes and T- lymphocytes. The manifestations are eczema, thrombocytopenia, proneness to infection, and bloody diarrhea. Death usually occurs before age 10.

Fanconis Anemia handbook; Lynn and Dave Frohnmayer.

With that, our seven-day and six-night stay at the Rockefeller University Medical Center was over. Although we were all exhausted when we got back to Arkansas, Henry drove straight to my mother's house to pick up our daughters. Finally, we were home, and everyone went straight to bed. Henry and I lay there for a while, discussing the boys' illness and Adam's upcoming bone marrow transplant. The more we talked about it, the more depressed I became. Suddenly, I began to tremble. Henry reached over and cradled me in his arms, saying, "Gwen, you shouldn't worry about things so soon. God may have Adam's problem already

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worked out. Laverne has a perfect match to his marrow, maybe that's His plan for Adam to be healed. Who knows?"

Hearing those words, I could not understand why God was taking us through so many trials when He could just heal our boys. It was awful enough that our boys were sick; now fourteen-year-old Laverne would be the donor for her brother in the hopes of saving his life. We didn't know what effect this might have on her; all we knew was that it was unbearable to think about.

"As Christians, we try to live a moral and a good life, with high standards. God has to know that we love Him, so I don't see any reason why He hasn't answered our prayers." As I said the words I could hear the bitterness creeping into my voice, and I knew Henry heard it too.

He looked deep into my eyes, and said, "God's will is going to be done. He allows these things to happen, not us. If it was left to you and me, they would never have a sick day in their lives, and they most certainly would never die."

Chapter 17

Making A Tough Decision

During our follow-up appointment with Dr. Ribeiro, he examined all three boys and gave Adam a

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blood transfusion. Junior had to have an IV of gamma globulin and Carl was fine with just his routine checkup.

"How was the trip to New York?" the doctor asked with a smile. "Did you guys come back with a different accent?"

"No, we still speak the same - *country*," Henry said. We all laughed, then Dr. Ribeiro got down to business.

"Did you get the information that you needed from Dr. Auerbach?"

"Yes," Henry replied, "She agreed with you about giving Adam the transplant. It was really hard, but now that the trip is over, we're glad Dr. Auerbach did all those tests on the boys. At least now we know what they have."

Dr. Ribeiro nodded. "Have you and Gwen decided what you want to do regarding Adam?"

"Not yet," Henry said. "Give us a little more time to think about it."

"Okay," said Dr. Ribeiro. "Just let me know as soon as possible. We don't want to keep prolonging this too long, because Adam is getting transfused regularly and it may start to pull him down."

When we got home from the clinic, I found the addresses and phone numbers of some of the patients whose mothers I had met at St. Jude. A few months before we went to New York, one woman had told me her son would soon be undergoing a bone marrow transplant. I decided to give her a call.

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When she answered the phone, I reminded her who I was, then asked, "How is your son? Did he have the transplant?"

"Yes, he had it..." she said slowly, "but he didn't survive."

When I heard the words, I felt as though the wind had been knocked out of me; I thought was going to collapse right where I was sitting.

"I am so very sorry," I said, my voice trembling.

"How are your boys doing?" she asked.

"They're all alright," I replied, swallowing back tears, "For the moment."

"Didn't the doctors want to give one of your sons a transplant?"

"Yes, but my husband and I have always been nervous about. Now, after what you just told me I am even more afraid. I was hoping to hear some good news."

"Well, that's probably the only cure they have for your son's disease. My son had something else." She paused a moment, then added, "Just because my child didn't survive, doesn't mean yours won't. It depends on how strong he is and how well he can accept his donor marrow and the strong medication he will receive. Who is his donor?"

"His sister," I answered.

"Then his chances of surviving the transplant should be good."

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"I know - that's what the doctors say, but I don't know if Adam is strong enough. He may look good, but he's had lots of blood transfusions in the past."

"I really don't know what else to say to you," the woman said, "except to keep your trust in God and do what is best for Adam."

After we hung up, I was desperate to hear something positive. I called another patient's mother, who had told me that her son had had two bone marrow transplants and was doing well.

"It has been ten years since he had it. He is now twenty-one years old. It was hard for both of us while he was getting the transplant." She paused for a moment, as if reliving the memory. "They didn't allow me or anyone else in the room except for his nurses and their assistants. Yes, I was afraid, but the transplant came out all right."

While this conversation had ended much better than the first, I was still not satisfied with the answers I had received. I called and visited other people to inquire about their transplant experience, and Henry asked people on the job for information. Our hope was that we might find an answer that would ease our minds. We prayed day and night, asking God to help us make the right decision. Henry talked to our pastor and a few local ministers, but even they didn't have a solution. We tried to console each other, but we had never felt so powerless.

I found myself at the edge of an internal cliff. I didn't know what else to do or who else to turn to for help.

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Late one evening, I took Adam with me to the grocery store. He followed me down the aisles, helping me grab the items we needed from the shelves. As we drove home, I realized this was a great opportunity to ask him how he felt about getting a bone marrow transplant. He had already spoken to the hospital psychologist about the dangers of the procedure. He knew how it was done and understood that the medicine would make him very sick. He also knew there was a chance he could die.

I gave him a quick sidelong glance, and then shifted my eyes back to the road. "If you had to make a decision about staying alive, what option would you take? Would you have the transplant, or just stay as you are and continue to get blood transfusions for as long as possible?"

My heart raced as I waited for his answer. I felt completely vulnerable, because I had already decided I do whatever he wished.

What came out of his mouth next was a surprise. "Mom," he said, ever so gently, "I am just a child. I am only eleven years old. I don't know what I need to do. Whatever you and Dad decide is alright with me."

I didn't reply, just continued driving in silence. Adam sat calmly looking out the window at the traffic, seemingly unconcerned about the situation.

A few days later, we went back to the clinic for the boys' routine checkup with Dr. Ribeiro. The three women on the bone marrow team entered the room and offered a curt greeting.

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“Have you made your decision about Adam getting the transplant?” one of them asked; then, without waiting for an answer, she said, “We think it is the best option for him. If he continues to get raw blood, he will eventually die; probably within a year or two, or maybe sooner.”

“Now that he has a second chance at life, with his sister as his donor, I think that you should give him that chance,” Dr. Ribeiro added.

We listened quietly as they made their statements and voiced their opinions. One part of me wanted to agree with them; the other part of me was angry because they were constantly pushing the transplant. I was even becoming a little suspicious of their motives; were they tired of trying to treat his condition and just wishing it would be over? A voice inside me said, “Hold on to your faith, God is in control. There is nothing they can do to harm Adam, unless God allows it.”

I just stood there, trapped, with all these thoughts running through my head. If we went through with the transplant and Adam died, we would feel guilty. On the other hand, if we did nothing and he died, we would also feel guilty. I realized that Henry and I had put too much of the decision-making in God’s hands, when the reality was that God had made us Adam’s parents so we could make these decisions for him.

After a moment, Henry slowly answered, “Well, I guess we’ll have to. From listening to the information that you have been giving us, it seems as though we don’t have much of a choice.”

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The doctors' relieved smiles turned to puzzlement at Henry's next words.

Henry asked, "What about Le Bonheur Children's Hospital? I've heard that the same doctor that works here works at Le Bonheur. I want to have Adam and my other boys transferred over there, then he can have the transplant."

"Why do you want them to be transferred?" Dr. Ribeiro asked.

"Because it's a regular hospital and not a research hospital," Henry replied, "I think they'll do better over there."

Dr. Ribeiro shook his head in disagreement. "St. Jude is the better place for the transplant; and yes, some of the same doctors who work here work there too. There is no need to have him transferred." After our discussion, the transplant team left the room, but we spoke to Dr. Ribeiro for a few more minutes. When it was time to go, I opened the door and took a single step out into the hallway. Suddenly I felt a cold breeze come over me. Everything became hazy and I felt like I was about to pass out. I pushed myself forward, and even though Henry and the boys were right behind me, I felt alone. I kept walking until I reached a warm space; I felt like it was bringing me back to life. I turned to Henry and the boys and asked, "Did you feel that cold and scary breeze?"

"No," they said simultaneously, and continued walking down the hall. The fact that I was the only one to feel it scared me all the more, but I figured it was just all the emotion of having finally made the decision. We

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were consenting to the transplant, but that didn't mean we were comfortable with it.

Our appointment was over, but we still had to pick up the boys' medication. As usual, we'd sit in the lobby until the pharmacy called to say it was ready.

A nurse walked over to where Henry and I were sitting. "I heard that you've agreed to let your son have the transplant."

"Yes, news travels fast around here, don't it?" I replied sarcastically.

She placed her hands on my shoulders and looked down at me until I met her eyes. "I most surely hope things work out for your son," she said sadly, then she turned and walked away.

I stared after her, feeling my suspicions return. Was that her way of telling me we had made the wrong decision, or was it simply her way of showing me sympathy?

Chapter 18

Dreams Do Come True

A few minutes later, I spotted a brochure about the Make-A-Wish Foundation. It was an introduction to the organization, but didn't give many details. Just then

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I saw our social worker, Chris Sinnock, walking down the hallway, and I waved her over. "Can you tell me about the Make-A-Wish Foundation?"

Her face lit up. "Are you all interested in it?"

"Yes, but I need a little more information about it." I paused for a moment, not knowing if I could ask the question. "Is it for ill children who might eventually get well, or is it just for children who are dying?"

"Yes, it is for terminally ill children, but fortunately, some children have gotten well." She smiled gently. "The Make-A-Wish Foundation is to help children get something they've always wanted, but not just because they are dying. Who knows how long a person is going to live? Only God knows the answer to that, right?"

"I want to be sure, because if the program is only for the children who are dying, I'm not interested."

Adam, who was playing with Carl nearby, had still managed to eavesdrop on our conversation. "Yes, Mom," he interjected, "put us on the program. Something could happen to us, you know!"

"Adam!" I scolded, "Be quiet, boy! Always think positively."

I glanced at Chris and, despite myself, began to laugh.

One evening, the neighborhood boys were outside playing football. When I looked out the window and saw that Adam and Junior were playing with them, I called for them to come inside the house. They didn't

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argue, but looked none too happy as they walked in and plopped down on the couch. I asked them not to play ball with the boys because I was afraid they would get hurt. They sat there pretending to be watching television, but I knew they were upset.

A few minutes later, Adam asked, “Mom, why did God pick us to be sick? I want to be like other children. I want to play football and have fun like other children.”

“Yeah, Mom,” Junior chimed in, “why did God pick us? Why didn’t He let it happen to somebody else?” Without waiting for an answer, he got up off the couch, went in the kitchen, and opened the refrigerator to look for something to eat.

But Adam wasn’t finished with his questions. “We are Christians, and we read the Bible and go to church all the time. There are children out there who will do anything; they will rob people, they’ll hurt people, and some even kill their own moms and dads. Why didn’t God choose them to be ill instead of us?”

I held up my hand. “Boys! You have to be thankful! You do have fun, you know you do. But because of your illness, you can’t always play the way other children play. And there are kids out there who can’t do the things you do because of their illnesses. There are some places you have gone, or may go, that they will never experience.”

When Adam and Junior didn’t say anything, I added, “I don’t know why this has happened to you, but it could have happened to anybody. Yes, you are good children, and you haven’t done anything to deserve being sick, but God doesn’t just use disease or

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misfortune to punish the wicked, nor does He save only those who are 'deserving'. You only have to walk into St. Jude, or other children's hospitals, to see the truth. Just because you're sick doesn't mean God doesn't love you."

They sat in front of the television for a while, quietly contemplating my words. Eventually, they went back outside. I walked behind them as they left. No sooner had I put one foot out the door when one of the boys yelled from across the street, "Can Junior and Adam play a game with us? We won't play rough. We won't hurt them, I promise."

"Okay," I called out, "but you guys had better be careful out there!"

Every parent and child in this neighborhood seemed to know how I felt about my boys getting hurt. I turned and went back into the house, but I found myself looking out the window every few minutes to make sure they were all right.

A couple of days later, and out-of-the-blue, Adam became distraught about his illness. He constantly asked his father, "Am I going to die from the transplant?"

I didn't know what hurt me worse - hearing Adam ask the question, or seeing the agonized look on Henry's face when he did. It was like someone was stabbing me in the heart. Finally, Henry gave the best answer he could. "Son, leaving this world is something we will all do. The good thing is, we don't know when or how we are going to leave. Whether or not a person will leave old or young, it's all in the hands of the Lord."

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It was around the same time when we realized Adam was sensitive to the supernatural. He began seeing things the rest of us couldn't - the kitchen doorknob turning when someone was about to enter the house, even though he was lying in his bed, or someone peeping around the corner of his bedroom door at him. One night, he fell asleep on the living room sofa while watching TV. Rather than moving him to his room; I just put a blanket over him and let him sleep. The next morning, Henry and I heard him call out and we hurried into the living room. He wasn't in pain, though; he was excited about a dream he'd had.

He told us, "An old man came from out of the hallway and into the living room, where I was. He had a walking cane. He reminded me of Abraham Lincoln. I don't know who he was, but I believe that he was your dad."

I shook my head, smiling. "My dad never used a cane and was only fifty-eight years old when he died."

"Yes, but he was old! I saw his picture at Grandmother's house. Then something else weird happened. My spirit left my body and I could see myself lying on the couch." My breath caught in my throat when he said that, but I didn't want to interrupt him. "Remember that day when I went with Dad to a funeral home, the man in the casket had on dark glasses. Well, I saw him messing with the heater that is sitting in the corner of our living room."

Even though Adam smiled as he told us the story, the tone in his voice and the expression on his face made me believe what he saw was real. But I couldn't

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understand why his spirit had left his body when he appeared to be doing fine. It frightened me something awful.

“Adam, I am sure it was only a dream,” I said, trying to put his mind - and my own - at ease. “You were really tired when you fell asleep.” But no matter how hard I tried, I could not make him believe that it was just a dream. He was so convinced it was real that he told the story to everyone that came to our house.

We continued to attend church and hoped that God would perform some great miracle on our children, like He had done in Biblical times, or that He would send some great man to heal our sons, just as Elisha did when he went into the house of a mother and restored her child’s life (II King 4: 35).

Adam loved singing in the choir and leading the congregation in spiritual songs. He started out in the Sunshine Band Choir, which was made up of pre-teens. There was also a Youth Choir for teenagers, as well as the Adult Choir.

That year, in honor of our church’s anniversary, we attended two nights and three days in a row. Most of the congregation dressed formally for the occasion, but on the last night, Adam decided to wear neatly starched jeans and a starched shirt.

He and Junior had been sitting a couple of seats ahead of me, but when the Adult Choir was asked to sing with the Youth Choir, Adam quietly got up from his seat and moved back to sit beside me. He leaned in and whispered, “Mom, I want to sing in the choir.”

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I leaned over and whispered back, "You are not old enough, you have to be at least twelve or thirteen to sing with the adults."

"Mom, please, just this one time," he pleaded. He sounded anxious.

"Adam, you're too young, and besides, you have jeans on. They will only send you back to your seat."

To my surprise, he began to cry. "Please, Mom, just this one time," he repeated. "If you let me sing, I won't ask you again."

My heart sank. I wanted so much to tell him to go up there with the choir and sing his little heart out, but I was afraid of what the choir director or some of the other choir members might say.

I told Adam to walk with me to the back of the church so we could talk about it in private. Then I asked him to be patient; he'd be twelve in a few months and maybe then they'd let him sing with the Adult Choir. I looked at my baby's tear-stained cheeks and dark-ringed eyes and wrapped him my arms. Suddenly, I had an idea.

"Adam, when the choir is singing, why don't you sing along with them from the audience?"

He seemed to calm down, but was not quite pleased with the idea. After we got home, Henry and I spoke to him about it. It wasn't personal; he simply wasn't old enough. I reached over and hugged him, then wiped his tears away. "If there were such things as an angel choir in heaven, I believe that God would place

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you right in the middle. You'd probably even be in the front row so He could see your happy little face."

That finally seemed to cheer him up, and he soon forgot about that night.

The year 1992 began with a wonderful surprise: our family was invited to the "Dream Come True" event sponsored by the Make- a -Wish Foundation. We drove to the Peabody Hotel in Memphis to meet with their representatives. As we walked through the entrance, we were greeted by television and newspaper reporters, who videotaped us and took pictures of the family. Adam was awarded a trip to Disney World, while Henry Junior received a camcorder and a VCR. Carl got a child-size toy car to ride around in. When the event was over, we drove back home, and that night the children gathered around the television and watched themselves on the evening news.

The following Wednesday, reporter from our hometown did a write-up in the local paper.

Trip precedes Vital Operation - Family Sticks Together

Henry Jr. inside Peabody Hotel, he shows off the camcorder the Make- A-Wish representatives granted him.

In just a few more days, Henry and Gwen McNutt, and their six children, will take off for an all-expense paid trip to Disney World, compliments of the Make -A Wish Foundation. There, they will try to have a good time and forget about their problems for a while.

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Then, shortly after they return, one of their children, 11-year-old Adam, will undergo what they hope will be lifesaving surgery.

Three of the McNutt children, Adam 11, Randall, 7, and Carl 3, have a type of anemia in which their bone marrow does not make enough blood. The oldest son, Henry Lee, Jr., also has another type of genetic blood disorder. All are regular patients at St. Jude Children's Research Hospital in Memphis.

Mr. and Mrs. McNutt do have some things to be thankful for. Their daughters, Laverne, 14, and Adrian, 5, are healthy. Also, Randall doesn't seem to be as seriously affected with anemia as his brothers. Adam is another story. "He's pretty much dying," said Henry Sr.

Medications no longer seem to work for him, and he has been getting a blood transfusion every week for two years now.

Adam's only chance, apparently, is a risky bone marrow transplant. The risk has been reduced considerably, according to Henry Jr., because Laverne was found to be a perfect genetic match for Adam. The closer the match, the less the chance of rejection.

Mrs. McNutt said it was a social worker at St. Jude who referred the family to the Make-A-Wish Foundation, which grants wishes to critically ill children. From the group, Henry Jr. received a camcorder and VCR. Carl got a small toy car to ride in. Adam got the trip to Disney World for himself and his family. They will leave January 18 and stay approximately six days. Upon their return, they will start looking toward the transplant. Henry Sr. said it isn't the type of circumstance he would have chosen for such a

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trip, but he said the family would try to make the most of it and have as good a time as they can.

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A few days after the event, we packed our bags and headed off to Florida. For the next six days and five nights, we would try to forget about our problems and just enjoy Disney like any other family.

The Make-A-Wish Foundation had rented us two hotel rooms and a van. Each morning we would get up and go to the Gingerbread House for breakfast. This is where we would sit and plan our day, and what attractions we would see.

Adam was proud of the "Give Kids the World" button that was pinned on his shirt. This button allowed him to get into any building or rides without having to stand in line. Due to his illness, it was important for him to stay out of the sun as much as possible. At every ride or attraction, security would recognize the button and escort us into the buildings or through the line of people for the rides.

For Junior, the best part was his camcorder. He asked his father to video him and his siblings enjoying the rides and other attractions. It was fun to see Adam pick up a live snake and a small alligator that had his mouth taped shut. He encouraged our other children to pick up and pet the animals too.

Before we knew it, the trip was over. Six days had seemed like two. We did not want it to end, but we came home feeling truly blessed for the amazing time

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that we'd had. Disney World was truly a Land of Enchantment.

Chapter 19

Unexpected Guest

It was an ordinary evening in March. I was cleaning the house, and Henry and our children were sitting around the dinner table, looking through the pictures that we had taken at Disney World when we heard a knock at the front door. When I answered it, the woman introduced herself as Mary Powell, a newspaper reporter from Memphis. She had seen us on the evening news and wanted to do an article for The Commercial Appeal. We welcomed Mary and two of her co-workers in for the interview, and a few days later, the story went to print.

TUESDAY, MARCH 3, 1992 - THE COMMERCIAL
APPEAL - LIVING ON HOPE AND PRAYER

By Mary Power

First, Henry McNutt Jr., 12, developed a lump under his arm. Then Adam McNutt, 11, started complaining of aches. Then Carl McNutt, 3, was plagued with fever; finally, doctors tested Randall McNutt, 7. Doctors now believe all four sons of Gwen and Henry McNutt are affected by two rare, deadly inherited blood

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disorders. The diagnosis comes after years of uncertainty and now is forcing the family in this Northeast Arkansas town to make tough treatment decisions.

On March 12, Adam is scheduled to begin treatment leading to a bone marrow transplant that will either cure him or kill him. It's a treatment his parents initially refused, and it is one Carl and Randall might eventually face.

"I asked the Lord, 'Why?' I don't see anything to explain why all this is happening to us," said Gwen McNutt, 37.

What is happening is that Henry Junior has Wiskott-Aldrich syndrome, Adam and Randall have Fanconi aplastic anemia, and Carl has both. The couple's daughters - Laverne, 14, and Adrian, 5, are healthy.

Dr. Ribeiro of St. Jude Children's Research Hospital in Memphis, some 50 miles from Wynne, said he has never seen anything like it and can't find evidence that anyone else has either. "I still don't feel we have a clear picture yet, primarily of Carl's condition," Ribeiro said.

Questions persist, despite consultations with a host of U.S. and Canadian specialists. In December, St. Jude's doctors took the unusual step of sending the boys and their parents to New York's Rockefeller University to be seen by Dr. Arleen Auerbach, an international Fanconi expert.

Doctors know this much. Genetic material Gwen and Henry McNutt inherited from their parents included at least two mistakes. Those mistakes did not affect their health, but when they met 18 years ago at the St. Francis

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(Ark.) County Fair, fell in love, got married and started a family, the mistakes surfaced in their sons.

Today, evidence of those problems is tacked to the living room wall above the telephone in the family's three-bedroom mobile home, which is within sight of Halstead Industries where Henry McNutt, 34, has worked for 16 years. There are four pages of handwritten instructions about whom to call and how to respond to uncontrolled bleeding, high fever, and other medical emergencies their sons have survived.

The first hint something was wrong came shortly before Henry Jr.'s first birthday, when his parents noticed a large knot under his arm. Then came the uncontrollable bleeding and easy bruising. The family doctor diagnosed leukemia and sent them to the Memphis clinic, St. Jude.

St. Jude doctors later ruled out leukemia, but they could not decide what was responsible for Henry Jr.'s worsening symptoms.

They tried different medicines. The internal bleeding left him screaming in pains. Doctors were nearly forced to amputate his toes and the tip of his nose. Once, his immune system went into overdrive, churning out so many antibodies his blood became dangerously thick, 90 percent thicker than normal. Gwen McNutt remembers Henry Jr. waking up at St. Jude during the blindness episode and hollering. "Am I alive?"

After Henry Jr.'s first two brushes with death, his father said, "It started to get to me. I just figured there ought to be something they could do. We never knew when it (Henry Jr.'s disease) would attack again." It was constantly on my mind.

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Then shortly before Carl's first birthday, the family doctor became alarmed when he did not react to a finger prick. Already worried because of Carl's small size and poor appetite, Gwen McNutt did not hesitate when he suggested Carl be seen by a specialist.

St. Jude doctors were still sorting through Carl's test results about a month later when Adam announced, 'If I don't see a doctor I'm not going to live,' Henry McNutt said.

For years, Adam had complained of stomachaches, fevers and weakness, but the family doctor always blamed a cold or the flu and sent him home. That day the McNutt's went looking for a second opinion. Dr. Curtis Patton of Forrest City took one look at Adam, then 9, and sent him to St. Jude.

"After Adam was diagnosed, I was stunned. I often thought, 'I don't know how this is. What's going to happen to my boys?'" Mr. McNutt said.

"Part of the problem," Dr. Ribeiro said, "Was that no one could quite believe that two very rare diseases would appear in the same family. It caused some amazement. It was further complicated because the symptoms and test results didn't clearly point to one disease, particularly in Carl's case." Dr. Ribeiro added that he could not recall another diagnosis that was so difficult.

Until doctors identify the genes responsible for both diseases, there is no way to even check Laverne and Adrian to see if they also inherited the genetic mutation.

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The genetic material, which provides the blueprint for human life, is organized into an estimated 100,000 genes carried in nearly all cells.

The system usually works well. Everyone receives two copies of each gene - one from each parent -so if one gene is defective, odds are good the other will fill in with the right instructions. The McNutt family represents the rare case in which each parent carries one good and one defective gene. That leaves each child with a 25 percent chance of inheriting two abnormal genes and developing the disease.

Now Dr. Ribeiro believes antibiotics and gamma globulin can help Henry Jr. battle infections and live to be an old man.

Wiskott-Aldrich primarily affects his disease-fighting immune system and the platelets that help blood clots. It occurs in 5 to 10 of every million male births.

Infections and bleeding are the highest threats to Wiskott-Aldrich patients, killing more than 70 percent. Henry Jr. will also have to be watched closely for signs of cancer, which develops in about 20 percent of patients.

But there are fewer options for Adam. Fanconi is a disease of the blood-producing bone marrow, meaning all his blood cells are affected. Infections or bleeding kills most Fanconi patients within a few years of diagnosis. Survivors go on to develop liver tumors or leukemia. Nationwide it is estimated there are 500 to 700 Fanconi patients. A bone marrow transplant, with an average cost of \$130,000 to \$200,000, is the one Adam and other Fanconi patients must have for a cure. Powerful drugs will be used to kill Adam's own diseased bone marrow

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and replace it with healthy marrow taken from his sister, Laverne.

"There is a 70 percent chance he will survive the transplant and be cured," Dr. Ribeiro said.

It was the flip side of that statistic, the 30 percent chance of death that initially prompted the McNutt's to refuse the transplant. "At the time I would have rather seen him die just like he was rather than a horrible death as a result of a transplant complication," Henry McNutt said.

But after talking to New York doctors, and to other parents who faced the same decisions, the McNutts gave their permission.

Adam said most of the time he just does not think about his health problems. "When I get scared, I play with the dog," he said. When asked about the upcoming transplant, Adam said, "I hate it because it will make me really sick."

Back when just Henry Jr. was sick, Gwen McNutt remembers locking herself in the closet and telling God she could not take it anymore. "I thought about drugs," she said. "Now I feel like they (the boys) are going to pull through."

The family's low point came in the summer of 1986. Henry Jr. was sick, Henry McNutt was burned in an on-the-job accident and it was 10 months before he returned to work. He was hospitalized in Memphis when he received word that his wife was hospitalized in Wynne. "I had a nervous breakdown," she said.

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"I think the McNutts are doing beautifully. I don't think I could cope like they do," Dr. Ribeiro said.

There is health insurance to help with the medical bills. However, Henry McNutt said he still worries about whether the truck will break down on the next trip to Memphis, about whether his sons would be healthier if they lived in a larger, warmer house, and about whether Adam will survive the transplant.

Even on a recent family trip to Disney world, a trip sponsored by the Make - A -Wish Foundation, Henry McNutt said their worries would surface. "We had a really nice time," he said, displaying photos from the trip. "But you just can't brush it off your mind. It's always there, worrying you."

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When we sat down for these interviews, we could not have imagined that role the news media would play in our future, or the faith it inspired in the human spirit. After the newspaper articles and television broadcasts, many people who hadn't known of the boys' medical condition reached out to us. We received phone calls, donations, and letters of encouragement from many of the people in our local town, as well as from others states. Our community and our churches held fundraisers and collected donations for Adam's bone marrow transplant.

One day, Mrs. Scott came to our house and asked if she could sponsor a benefit basketball game for Adam

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after he returned from the hospital. Moved by the gesture, I gratefully accepted.

"Daniel's Demons and Willie's Warriors will play the game in the school gym," Mrs. Scott said. "If the team that is playing for Adam wins, they will be presented a basketball trophy."

She stayed and chatted for a while, then said she had to be on her way. She stopped at the door, turned toward me, and said, "I hope to see Adam walk down those stairs and receive that trophy. And I hope to see you and the rest of your family there too, Mrs. McNutt."

I thanked her again and said we would try our best to be there. I walked her out, thinking how incredible it was that she was going out of her way to help others. Unfortunately, Mrs. Scott would have to face a heartbreak of her own before the benefit could take place. Her oldest son, who was about to graduate from high school that May, died in his sleep. I never learned the exact cause of death, but my heart went out to her.

One of my sisters was a friend of Mrs. Scott's, and when she told us the news, we went to her home to offer our condolences. A few days later, her son was laid to rest, and while I did not attend the funeral, I prayed fervently that she and her family would get through this awful time.

My sister did go to the funeral to support her friend. Afterward, she stopped by my house to tell me about it. She said Mrs. Scott held up well. She also mentioned that her son had looked so peaceful, lying in the casket in a cream-colored suit.

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Adam had been in the room during the conversation, and I knew he was listening intently. After my sister left, Henry and I went to our room to rest. Suddenly Adam walked into the room, looking ever so happy, and announced, "If I die I want to wear a white suit, and I want a white casket, too."

Henry and I turned to him in amazement. "Why did you say that?" I asked.

He laughed and said, quite matter-of-factly, "So that you and Dad will know what I want if I die."

"Adam, we are not looking for you to die. We are only thinking positively and we are hoping and praying that you live."

He just laughed playfully, then left the room.

On Thursday evening, before coming home from work, Henry was able to get a leave of absence from his job so that he could be with Adam during the transplant.

On March 12, 1992, Adam and Laverne were scheduled to be admitted to St. Jude. Earlier that morning, Mrs. Barbara, who owned a small convenient store in Wynne called the B and G Grocery, called and asked if we could come by the store and pick up a donation before we left for Memphis. Prior to leaving the house, Henry and I called the children in the living room for a family prayer.

We prayed that Laverne would continue to be strong after she gave marrow to her brother, and that Adam's body would accept her bone marrow and be healed from this terrible disease. Afterward, we gathered our luggage, Junior's camcorder, and our

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camera, so that we could record Adam and Laverne's experience with the transplant. Our hope was that after the transplant he would be able to view the videos and photos and thank God for bringing him through this horrible experience.

When we arrived at the B and G Grocery store, a newspaper reporter from Wynne and a television reporter from Jonesboro greeted us. The newspaper reporter took a picture of the store manager with Adam and me. The television reporter interviewed us. On the video, Adam said he wanted to be able to play like other children and eventually become a football player.

Then, after the manager gave us the donation, we thanked her for her kindness and left for St. Jude. During the long ride, Adam sang a gospel song that he had once heard and loved. *"There is no need to worry of what tomorrow is going to bring. It will be all over in the morning."* Hearing his beautiful voice, I thought about the transplant and silently began to grieve. After he finished singing, he started laugh and play with his sisters and brothers. He was joyful and his energy seemed boundless.

An hour or so later, we arrived at St. Jude. The family got out of the van and walked together down the cement walkway toward the hospital. I dreaded walking into the building. I felt horrible, but tried to believe that Adam would be all right. One part of me wanted to turn around, lead Adam and the rest of my family back to the van, and return home. I did not want to think of the bone marrow transplant anymore.

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As we approached the building, we passed Dr. Wang.

“Hi McNutt’s, how is Adam?”

“Adam is doing fine,” Henry answered.

“He’s supposed to get started with the transplant today, isn’t he?”

Henry nodded. “Yes. Today will be his first day, or maybe tomorrow morning.”

“Well, good luck, and you all take care,” Dr. Wang said.

We thanked him and headed into the building.

Once inside, we crossed the lobby area, then down a hallway past a bank of elevators. Beside one of the elevators, we noticed a newspaper article stapled on the bulletin board with our picture on it.

As we continued down what I called “the hall of horror”, we passed people who had seen us on the television news and read about us in the paper. One person spoke up and asked, “How does it feel to be famous?” Then someone else yelled across the hall from another wing, “Here comes the famous McNutt family! How are you guys doing? How is Adam?”

We smiled and spoke back, but it was all a bit unnerving. I didn’t feel “famous”, just terrified. My son’s life was on the line, and they were being flip about the whole thing. Adam and our other children enjoyed the attention; it made them feel important. Well, at least it kept their minds off what lay ahead, if only for a few minutes.

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The treatment began that evening. A nurse came and took Laverne to the room where she would draw the marrow. Adam was put in a different room, where he would undergo chemotherapy to destroy his own marrow. Afterward, he would receive his sister's bone marrow. The treatment would take several days.

In the beginning of the transplant, Dr. Ribeiro had to leave to attend to an emergency in another city. Henry and I became extremely upset that we had to deal with a new doctor at this critical time. We were not certain what he knew about Adam's rare disease, or how he would handle the transplant. Regardless of how we felt, the treatment had already begun. There was no turning back.

Late that Sunday evening, Henry drove our other children back to Wynne so they could go to school the next day. He left them with my mother, then returned to the hospital to be with Adam.

The second week of Adam's transplant, our children were on Spring Break. Henry drove back to Wynne, picked them up from Mom's and brought them back to the hospital. Despite the circumstances, I felt better that we were all together.

Adam was put in quarantine to avoid infection, as his immune system was weakened from the chemotherapy. The "parents' room" was connected to Adam's, and had a large, glass window above a three-foot high wall. Once the children were situated, they were allowed to talk to Adam through a microphone from inside our room.

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Randall brought some pictures that he had drawn and colored in. He taped them up against the window for Adam to see. "Adam, I brought these for you!"

Adam raised his head and looked toward the window. He saw the pictures and cracked a smile. It was apparent that he was weak from the high doses of medicine he had received for the transplant.

"Yes, I see them," he replied in a weak voice. "They're pretty Randall, thank you." Exhausted from just that little bit of interaction, he laid his head back on the pillow to rest.

On the third weekend of the transplant, I drove our other children back to Wynne so they could continue school. When we got to my mother's house, she greeted us with tight hugs, then we went inside and sat at the kitchen table to talk. I reached into my purse and brought out a few pictures of Adam I had taken for her. His skin color was not normal, and he looked pale and weak. Despite this, he had managed to smile for the camera. As she looked at the pictures, my mother hung her head in sorrow.

"How is he?" she asked as she handed me back the pictures.

"He is okay."

She looked at me doubtfully, and I could see that her heart was heavy.

"He has already had his second week of chemo. He should gradually gain his strength back after he receives Laverne's bone marrow. The doctor warned us

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that the medication would make him sick. They told us it would take a few days before it kills all of his marrow. Don't worry, I think everything is going to be all right."

After doing my best to convince her that Adam was going to pull through, I kissed her and the children and walked to the door. "Well, goodbye!"

"No! Don't you say goodbye! Don't you say that word!" Mom shouted, without even a trace of a smile. She seemed terrified. "I want you to say, I will see you later." Stunned, I could not say a word. "Say it now!" she demanded. She sounded as though if I did not say the words, some evil spirit would curse me.

"Okay, Mom, I'll see you all later," I said with a smile. She seemed relieved. I left the house to return to the hospital.

The next day, Henry and I did our best to keep Adam awake and alert. We were allowed to enter his room with a mask, apron, and gloves on. A nurse came in and noticed how drowsy he had become. His appetite was poor and he was not interested in watching his favorite television shows or playing video games. This was not normal for Adam. The nurse looked at us and announced, "I am going to send a physical therapist in to work with him. Hopefully it will help him stay awake and give him some energy."

A little while later, the physical therapist arrived with a stationary bicycle. "If he is doing all right, and I am not here, you can get him up out of the bed and let him do a few minutes on the bicycle. We don't like for the children to lie in bed too long because they lose their energy." Later, Henry and I helped Adam out the

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bed to get on the bike. After he did a few minutes of exercising, we put him back to bed.

Around eight o'clock that night he started complaining about pain in his lower stomach. I got a nurse, who in turn called for the doctor in charge to examine him.

He pressed on Adam's abdomen for a bit, then calmly turned to us and said, "I don't feel anything. I don't know what is causing his stomach to hurt. Sometime patients develop diarrhea after they receive strong doses of medicine."

After he'd left the room, Adam's stomach continued to hurt. I was sure the doctor could do something to help him; so again, I called for him to come back in the room. Again, he examined Adam's stomach, and again, he found nothing.

"I'm in regular contact with Dr. Auerbach and Dr. Ribeiro," he said, "and the next time I talk to them, I'll tell them what is going on here with Adam. They'll know how to handle it." His words did little to reassure me, and as I feared, Adam's condition continued to worsen throughout the night. Henry and I were in panic mode. We barely slept and couldn't even think of eating. Finally, the doctor requested that our son be moved to the ICU unit.

But when Adam heard the doctor's request, he shook his head and said in a very weak voice "No, I don't want to go in there!"

"Why not?" Henry asked.

"Because all I will do is become worse."

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Our hearts ached for him, but we knew there was no choice.

The nurse readied his bed and pushed him out into the hall. He didn't have far to go: the ICU unit was right across the hall from his regular room. As the nurse pushed the bed, she told him, "This is the best thing for you, Adam. We can help you better in there and someone can watch you at all times."

Once in the room, Adam was shifted to another bed that looked more comfortable. The nurse then hung a bag of morphine on his IV pole; it was attached to a CADD pump so he could access it whenever he needed to. "This way you won't have to call out for us whenever you're in pain," she said kindly, "Just push the button and the machine will automatically give it to you."

Adam's eyes were very red and his faced was puffed and pale. We could see he was extremely weak and uncomfortable. Yet, in all our despair, Henry and I managed to keep the faith. We were praying for him, as were so many people we knew, and we refused to believe that he was not going to pull through. I retrieved Junior's camcorder to make a video of him, while Henry stayed by his side. I began to videotape him as I entered the room.

"Mom, stop! Don't video me!" he exclaimed with all strength he could summon.

"Why not? Let me shoot one more, okay?"

"No, Mom, don't!" he insisted.

Disappointed, I set the camcorder down and went to his bedside. I had imagined that one day soon

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we would all be sitting on the couch at home, watching the videotape and filled with gratitude that Adam had made it past this horrible experience. The videotape would be evidence of our faith.

A nurse entered the room, hooked up the oxygen machine, and put a tube in his nose. After a few hours I could tell that the tube was uncomfortable; Adam wanted to take it out. When the nurse came back to check on him she too noticed his discomfort and did her best to help. She removed the tube, put an oxygen mask over his face, and turned up the oxygen. When she finished she left the room, with Henry close behind her.

By the time he returned, I had once again turned on the camera. "Just a few minutes," I said, trying to coax a smile out of my son. One glance at Henry, however, and I knew that something was terribly wrong.

He said nothing at first; he just walked over to a chair in a corner of the room and quietly sat down. I wanted to ask what was wrong, but I remained quiet, not ready for another blow.

Suddenly he blurted out, "Gwen, don't do any more videos! Just take the camcorder out of here!"

I looked at him, startled. "What is going on? Why are you looking so sad? Adam is going to be all right!"

Henry said with tears in his eyes, "Gwen, I really don't want to talk about it right now!"

"But what is it?" I asked quietly, my heart starting to race.

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With a look of sorrow, he shook his head. I knew the nurse had told him something when they were in the hall outside Adam's room.

It wasn't until later that I learned what it was. The nurse had observed that Adam was having some difficulty breathing, and it seemed as though he had other problems that were becoming serious as well.

"It's possible that Adam is developing Graft Versus Host Disease (GVH)," she had told Henry, then went on to explain that GVH occurs when certain lymphocytes (T cells) from the donor recognize the patient's cells as foreign and attacks them. But Henry already knew what it was, and so did I, because we had been briefed before the transplant. This is what we all feared, what we had been warned could happen.

As the days progressed, things only got worse for Adam. Henry and I refused to leave him alone; not even for one minute. We took turns staying with him, trudging up and down that long, deathly hallway from the parents' room to the ICU. Neither of us had an appetite for food; instead, we lived on a diet of hope and prayer.

In the thirteen years we had been visiting St. Jude, I had seen many parents walk this hall in fear for their children's lives. I had heard countless people screaming and crying because their child, grandchild, niece, nephew, or friend was either close to death or had just died. Yet I could not believe, I refused to believe, that it was time for my child to rest in God's arms. Despite their own suffering, several other parents,

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as well as the hospital workers, came to our room and prayed with us for Adam's recovery.

Adam continued to grow weaker, and during the fourth week of the transplant procedure, he slipped into a coma. Terrified but undeterred, I read to him from the Holy Bible, and even kept a Bible under his head.

One day, during shift change at the hospital, a nurse came in to check on Adam, followed by another nurse who would be caring for Adam for the next several hours. By this time, Adam had been placed on life support. His kidneys were not working properly and we knew his life was in grave danger. As I listened to one nurse giving the other instructions for his care, I was gripped by a sudden panic. I was convinced that they were not giving him enough attention. I felt they were not doing all that they could for him.

"He doesn't need anyone in here to be instructed!" I said angrily, "He needs a specialist! Don't you see how sick he is?"

The nurse turned toward me and said, "If I don't show her, who will handle this situation after I leave?"

"But this is not the time to teach someone! Adam needs all the attention on him! Please go and get him a specialist!"

Neither nurse responded to my outburst; however, at my request, they did leave the room. I'm sure they realized I was just reacting to the situation, just as countless other parents had undoubtedly done. A few minutes later, another nurse came in to assist Adam.

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The bed was positioned in such a way that his head tilted forward and down and his feet were positioned up. I am not sure why that was. Henry and I noticed that his head and face had begun to swell, badly. I asked the nurse to raise his head so the excess fluid would not continue to settle in his head and face. The nurse kindly raised Adam's head, and then Henry combed what little bit of hair he had left. He had lost most of it from the high dose of medication. Within a few days, it would all be gone. His condition had deteriorated to the point where a nurse sat with Adam around the clock in order to keep a close watch on him.

The next day Henry left for home. He needed to return to work, but he would ask for an extended leave of absence, at least for one more week. I stayed with Adam, never leaving his side. The nurses had continued to give him more fluids, and his body continued to swell. That day, Adam was so swollen that he was nearly unrecognizable. I did not understand what was happening.

A nurse who had worked in this ICU unit for thirteen years saw my fearful expression and told me not to worry; that even though this looked like an ugly picture, Adam would probably be all right. "Some children swell up and still get better," she said encouragingly. Hearing this calmed me, at least for the moment.

Adam had reached the point to where he had no bowel movement and he was not able to urinate on his own. A nurse inserted a catheter, hoping that he would pass some fluids into a bag. It worked for a while, but

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eventually that ceased as well. The nurse ordered a small machine from another hospital to help the urine pass directly from his kidneys, but that too turned out to be a temporary solution.

Late that evening, Henry returned to the hospital. When he walked into the room and saw the bloated body of our son in the bed, his face froze in horror. He couldn't believe that his appearance had changed so drastically in such a short period of time. I quickly told him what the nurse had said, that despite how bad it looked, there was still a chance he would get better. That calmed Henry down a little.

But Henry had other problems as well. He had arrived back in Wynne to request his leave of absence, only to be confronted by a short, round man in his early thirties who also worked at the factory.

"Because you keep taking off from work to go and check on those rejected ass boys of yours, I have to work out on the floor!" The man yelled, then paused to spit out a thick, brown wad of chewing tobacco. "I want to become assistant lead person while Johnny (another co-worker on leave) is away. I can't do that now because they need an extra man on the floor." The man spit again, spewing brown juice everywhere, then repeated, "I've had it with you and those rejected ass children of yours!"

"I walked away," Henry told me, "I just couldn't believe someone could be so selfish."

I shared Henry's anger and disappointment, but I knew we had to focus on Adam and continue to keep up the faith. We just could not give up on God. We hoped

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and prayed that somehow, God would perform some type of miracle and Adam would be all right. During the last few days of our stay at St. Jude, several of our family members had come to visit with Adam and watch over him so Henry and I could rest.

On the Monday of the fifth week of the transplant, I walked out into the hall to find Henry speaking to Dr. Ribeiro. I was furious. He had finally returned to the hospital, too late, I felt, to help Adam. I turned and walked back into Adam's room. After a few minutes, Henry came in and told me that Dr. Ribeiro wanted to have Adam transferred by ambulance to a different hospital in Memphis. It was just a few minutes from St. Jude. This other hospital specialized in helping the critically ill, and Dr. Ribeiro thought that maybe the physicians there could revive him.

However, once he came into the room and saw Adam, the doctor had a change of heart. It wasn't just the swelling; his absolute neutrophil counts (ANC) was below one, he could no longer fight infection, and he had blood flowing from his mouth. It was clear that death was imminent. Henry and I left the room to sit in the lobby while Dr. Ribeiro examined him.

An employee stopped us out in the hall and asked, "Why did you bring him here? Didn't you know this is a Research Hospital? Look out there on the building and you will see a big sign that says, 'St. Jude Research Hospital!'"

If the circumstances were not so dire, Henry and I might have responded to her callous remark, but we were too scared and devastated. When I thought about

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it later, though, I was angry at her accusatory tone. It seemed as though she blamed us for taking Adam there, as if we were to fault for his ordeal. Did the fact that St. Jude's was a research hospital mean doctors had the right to experiment on my child for their own education, rather than trying to cure him from this rare blood disorder?

It certainly seemed that way. The next morning, Tuesday, April 14, 1992, some specialists brought a machine into the room to check to see if Adam's brain was still functioning. Thank God, it was. One of them later informed us that, other than his heart and his brain, the rest of Adam's body seemed to have completely shut down. She then asked if she could remove a part of his liver so they could try and understand why it wasn't functioning properly. We were desperate and agreed to let them. About two hours later, we were told that Adam was close to death and there was nothing more they could do. Henry and I could only hope that whatever the doctors learned from Adam's liver would help them save someone else.

At 4:00 p.m., our beloved Adam went to rest in God's arms. My sister, an LPN, and a couple of cousins were in the room with Henry and Adam when the doctor pronounced Adam's death.

A few minutes later, my sister and one of my cousin's walked into the ICU lobby where I was sitting. They slowly approached me and said that Adam had been declared dead. They explained that the nurses had cleaned him for the undertaker, who would be arriving soon to pick him up. "Go and see him," they said. They

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described how peaceful he looked, with no tubes in his nose, no lines running out of his chest, and no monitors on him. No matter how peaceful he looked, I still could not take the pain of seeing my eleven-year-old son lying in his bed, dead. I was thirty-seven. As a parent, I had always hoped that I would grow old surrounded by my children and, one day, grandchildren. When I died, they would all attend my funeral. Until this moment, I could never have imagined that I would attend one of theirs.

A few minutes later, Henry walked into the lobby. His eyes were red and swollen from wiping away the tears. "Adam is gone, and he is at rest," he quietly said.

Moments later, a few of the nurses, doctors, and hospital workers came into the lobby, some with tears in their eyes, and told us how sorry they were about his death.

I thanked them, wondering why I could not cry. It seemed like every muscle in my body was tied in a knot. Henry and a nurse helped me out of the chair, then we went to our room, got our things, and carried them down to the van. I felt like a zombie; completely void of emotion. As we walked down the hall toward the door, I tried to accept Adam's death, that he was no longer in pain, and that no more harm would come to him.

Somehow, we made it to the van. I barely remember getting in. Henry and I said very little on the drive to my mother's house. It was as if this were a dream. When we pulled up to the house, Randall and Adrian were out in the yard playing. As soon as they saw the van they ran over to open our doors.

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"Where is Adam?" they asked, laughing as they looked in the van for him. "Did you leave him there?" Randall asked.

Henry glanced at me sadly, wondering how he was going to break the news. Just as I began to explain, Laverne and Junior came outdoors to greet us.

When she heard what happened, fourteen-year-old Laverne completely fell apart. "NO, Mamma!" she cried, "No! Not Adam!" Screaming hysterically, she fell to the ground. We both got out of the van to hold and comfort her.

Twelve-year-old Junior burst into tears as well, sobbing, "I just can't believe this has happened. Not Adam!" We all went into the house and sat in the living room in stunned silence. "Not Adam!" Junior repeated suddenly, "I just can't believe Adam died. He was strong and helped me out when I was sick. He always said funny things or did funny things that made me laugh and feel better." Then he added. "I can remember when I was afraid to get out of bed at night and go to the bathroom. Adam was brave. He would go with me, and even lead the way. But now he is gone!" Tears poured down his cheeks.

I looked around and realized that seven-year-old Randall was not in the house; he had continued to play outside as though nothing had happened. It was apparent that he was in a state of denial, and while I certainly understood it, I was also very worried. I went outdoors, and brought him into the living room with the others. We sat together on the couch, with me holding

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him in my arms and repeatedly telling him that Adam had died.

"Yes, I know," he said sadly.

Adrian, who was only five, took the news of her brother's death very hard. Even at her young age, she understood that she would never see Adam alive again.

Even three-year-old Carl knew that something terrible had happened. After all, everybody was there except his big brother Adam. Carl sat on the couch, rocking back and forth, as tears rolled down his cheeks. "I want Adam!" he sang the words over and over again, "I want Adam!"

My mother was completely heartbroken. Her reaction when she heard the news was anger. She walked into the kitchen and began rapidly stirring the food that was in a skillet on the stove. She stared at it as she stirred, as if she was in another world. What I could never figure out is, was she angry with God, or with us?

Stunned and exhausted, Henry, the children, and I finally headed into the bedroom. I suggested we all just lay across the bed and try to rest. First, though, Henry asked us to hold hands and pray.

"Lord!" Henry said, his voice thick with pain, "We know that you are going to take good care of Adam; we love him, but You love him best!"

We had known how very ill Adam was; we may have even thought that we were prepared. But that day we learned that nothing in this world can prepare you for your child's death. As a parent, you are always

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hoping and praying for the best. You never want to accept that this could happen.

We all slept together in one room that night. The next morning, when we awoke, Junior came to stand beside the bed. "Mom, I had a bad dream last night that Adam had died. I am so glad that it was only a dream." He managed a small smile, but I could see the sadness in his eyes.

I know he wanted me to say yes, that it was all a bad dream; that everything was all right. No matter, as difficult as it was, I had to make him understand that it was not a dream. "No, darling, it wasn't a dream. It's true; your brother passed away, and I know that we are going to miss him terribly."

With those words of confirmation, all strength left his body. He instantaneously plopped down on the foot of the bed, put his head in his hands, and began to sob.

That morning, Henry called his work to inform them that Adam had passed, and the news spread like wildfire throughout our community.

Many people called us to say how terribly sorry they were, even the man who had cursed Henry for taking time off from work. I do not know the circumstances, but apparently he was in jail when he heard about Adam. He called Henry and told him how sorry he was for our loss, and for what he had said about the boys. Another person might have reacted in anger, but, true to form, Henry accepted his apology. Besides, we had no time for anger, or even for our own heartbreak. We had to make the funeral arrangements.

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Henry and I managed to pull it together long enough to take care of everything, with the exception of choosing the casket. The hardest part was shopping for a nice white suit to bury Adam in. He had told us that if he died we should dress him all in white, and we wanted to honor that request.

We bought the suit, then returned to my mother's house, drained and depressed. Somehow, Henry found the strength to go to the funeral home to pick out a casket. He bought the best one he could find. It was white with gold trim, and shined with a heavenly glow when the light hit it. Before Henry left the funeral home, he told the funeral director that we wanted a closed-casket service; he was not to open the casket for anyone. The chemotherapy and transplant had caused Adam's appearance to change, drastically. We also knew there would be talk about our allowing the bone marrow transplant. More importantly, we wanted our son to be remembered as the joyful child he was, not the sickly figure he became in the hospital.

It was a good thing Henry made the request, for a few people did ask the funeral director to open the casket so they could view his body. He refused, per our request; however, Henry did take Carl and Randall to see Adam before the service. They wanted to see their brother one last time. As for the rest of us, we wanted to remember him just as he was before those terrible last days.

The Commercial Appeal News Paper wrote of Adam's death:

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Memphis - Thursday, April 16, 1992 - The Commercial Appeal

DEATH

Rare disease claims boy life after bone marrow transplant fails.

Adam McNutt, an 11-year-old Wynne, Arkansas boy who is one of four brothers with rare inherited blood disorders, died Tuesday at St. Jude Children's Research Hospital.

"He died of complications related to the bone marrow transplant doctors had hoped would cure him," said Dr. Raul Ribeiro of St. Jude.

Adam suffered from Fanconi aplastic anemia, a rare inherited blood disorder. His brother, Randall, 7, also has the disorder. Another brother, Henry, Jr., 12, has a different inherited blood disorder, Wiskott-Aldrich syndrome. The remaining brother, Carl, 3, has both disorders.

They are the sons of Henry and Gwen McNutt; the couple's two daughters are healthy. "I think the family is reacting normally. They have a lot of guilt and a lot of anger at the same time," said Chris Sinnock, a social worker from St. Jude.

The family's unusual medical problems have brought them to the attention of international medical experts. In 1991, St. Jude took the rare step of sending the entire family to New York City to be seen by a leading Fanconi researcher. Early this year the family visited Disney World on a trip sponsored by the Make-A-Wish Foundation.

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Nationwide, it's estimated there are 500 to 700 people with Fanconi, a disorder affecting the blood-producing bone marrow. Infection or bleeding kills most Fanconi patients within a few years of diagnosis. Survivors go on to develop liver tumors or leukemia.

Bone marrow transplants offer Fanconi patients the only hope of a cure and doctors had estimated there was a 70 percent chance Adam would survive and be cured. The transplant involved destroying Adam's own diseased marrow and replaced with healthy marrow taken from one of his two healthy sisters. Funeral arrangement was incomplete.

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The funeral was held at noon that Saturday, April 18, 1992. The casket remained closed, but a portrait of Adam was placed on an easel in front of it. As I sat there, numbly accepting the condolences of family and friends, I was torn inside with both hurt and anger. Despite everything the doctors had told us, I couldn't help feeling that more should have been done to save my child. Regardless, I had to be strong. I knew Adam would want it that way.

Adam was buried in our family plot at the Paradise Garden Cemetery, forty miles from Wynne. After the burial, we went back to my mother's house, where we would remain for the next few weeks. We simply could not face our home without Adam.

Maggie A. Griffin wrote of Adam:

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In Loving Memory Of Adam Lewis McNutt

Passing Through -

He came here with a lot on his mind

but he knew it wasn't much time.

*Other children were running and playing in the
sand*

so he told his Lord, he didn't understand.

*His Lord said, remember you are just passing
through*

I know that cross you carry is heavy, that is true,

But I have a son that carried it too.

The Wynne Progress (our local paper) wrote:

Wynne, Arkansas April 22, 1992

Adam McNutt loses fight with disorder

*Adam McNutt, who has been the focus of several
fund-raising events in Wynne, lost his battle with a rare
blood disorder and died last Tuesday at St. Clair
Children's Research hospital. Adam, 11, died of
complications related to a bone marrow transplant.*

*He suffered from Fanconi aplastic anemia, a rare
inherited blood disorder. He was the son of Henry and
Gwendolyn McNutt.*

*His three brothers are also ill. Randall has the
same ailment as Adam. An older brother, Henry Jr., 12,*

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has Wiskott -Aldrich syndrome, which is also an inherited blood disorder.

The youngest son, Carl, who is 3, has both disorders. The McNutts have two healthy daughters, Laverne, 14, and Adrian, 5. The family was given a trip to Disney World in January, sponsored by the Make-A-Wish Foundation.

There will be a benefit basketball game for the McNutt family, and for the family of Kathy McKnight, this Friday at 7 p.m. in the old Wynne High School gym.

Daniel's Demons and Willie Warriors will play. Admission will be \$2 for adults and \$1.50 for children under 12.

Two days later, it was time for the benefit game that Mrs. Scott had sponsored. I felt too depressed to go. Then I thought about Mrs. Scott, who had also recently lost her son yet still found enough strength to sponsor the benefit/fundraiser. I thought I owed it to her to find the strength to be there.

Many people attended the game. The Willie Warriors won. A large trophy was to go to Adam, only Adam was no longer here to receive it. His oldest brother Henry Junior proudly got up and ran down the bleachers to the gym floor. He happily accepted the trophy and raised it high above his head. My heart nearly broke with sadness, and with pride, as he waved it in the air, with a joyful expression that said, "This belongs to Adam."

Chapter 20

Coping With Our Loss

While Adam was having the transplant, our other children had stayed with us at the hospital. In the days before and after the funeral, we didn't leave each other's sides, and before we knew it, they had missed three weeks of school. It seemed everything had been a blur since the ordeal began.

One day I answered the phone to hear Randall's third grade teacher on the other end. She was calling to check on the family. We spoke for a few minutes, then she asked, "When do you think Randall will be able to return to school?"

"I don't know," I replied truthfully. "Right now I am so depressed, I feel as though I am at the end of my world. I don't have the strength to get them ready for school!" I paused for a moment, trying to control my voice. "The fact is, I see no need in sending Randall, or any of my boys, back to school when they may die before they even graduate!"

The line was quiet, and I knew she was at a loss for words. After a moment, she said, "Mrs. McNutt, I am very sorry to hear about Adam, and I know that you are very depressed right now, but you do need to let Randall come back to school." Her voice softened. "It will be a good thing for him, and he needs to be around other children."

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I realized she was right, that I was not acting rationally. The following week, Randall and our other children went back to school. One day, after Randall had returned home, I looked in his folder to examine his schoolwork. Inside, he had several sheets of paper with Adam's name written all over them. He had also drawn a picture of Adam lying in the casket, with the words "bone marrow transplant" written beside it. When I saw this, I felt empty inside. I knew that my seven-year-old child was carrying a terrible burden and I had to find a way to help him. I picked up his folder and called him to me. "Why are you writing Adam's name and drawing pictures of him in your folder instead doing your schoolwork?"

"I don't know," Randall said. "I guess because I think about him all the time." He looked up at me, and was quiet for a moment. Then he said, "And Mom, I think that I am going to be next to die." He tried to appear calm, but I could see the fear in his eyes.

When Henry came home from work, I showed him Randall's folder and told him about the conversation we'd had. He looked as upset as I was, but his voice sounded normal - even upbeat, as he asked Randall to go for a ride with him and get some ice cream.

I don't know exactly what was said, but while they were out Henry found a way to console him and lift his spirit. After that, Randall seemed all right, but I couldn't be sure; he had always been one to hide his feelings.

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Everyone in the family was carrying a heavy load of anger and guilt. We all blamed ourselves, or someone else, for Adam's death. We blamed our pastor and family for not giving us enough support, especially concerning the tough decision to let Adam have the transplant. We blamed Dr. Ribeiro, and the women who worked with him on the bone marrow team, for not being there at the hospital to support Adam, or us, during his final weeks. And we blamed ourselves for being too hasty in approving the transplant. Maybe, we should have let Adam continue to get blood when his hemoglobin was low, rather than going through with such a drastic procedure. But even in our lowest moments, we never blamed God. We knew that He never makes mistakes. We knew if He had wanted to heal Adam from that terrible disease, He would have. We also knew that He did not have to allow Adam to be sick in the first place. We realized there had to be a divine plan for Adam. We just did not know what it was.

Despite our belief in God and all His wisdom, we still had mountains to climb. We missed Adam terribly. There were times I felt as though I wanted to die to escape the overwhelming grief. I wanted God to come, take me off this earth, and place me in heaven with Adam.

I also kept a close watch over Henry. There were times when I thought he would do something crazy, like commit suicide, because he could no longer take the pain. There were times when he watched me because he thought I might do the same. We also kept a close eye on our children to see how they were dealing with the pain of losing their brother. My mother looked out for all of

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us as well. Whenever she saw Henry and me sinking into despair, she reminded us that we had other children who needed our support.

They too were all grieving in their own way. Junior blamed himself for not telling Adam not to have the transplant. Moreover, he wished that we had never let Adam have it. And even though Carl had gone to Adam's burial, he wouldn't let us pass the funeral home without asking to be taken back there. It was the place he had last seen his brother, and was convinced Adam was still there. Adrian and Laverne also felt guilty; they wished they had told us not to let Adam have the transplant. I often wondered if our daughters also felt guilty that they were strong and healthy, while their brothers were all dealing with severe illnesses. Yet, underneath it all, our family took strength in knowing that we had done everything possible to save Adam's life. We also knew that the doctors had done what they thought was best. We tried to keep moving ahead and relied on scripture, such as Revelations, to keep up going: *And God shall wipe away all tears from their eyes; and there shall be no more death, neither sorrow, nor crying, neither shall there be any more pain; for the former things are passed away. (Rev. 21:4)*

Before we learned that Adam needed a transplant, we had started construction on a new home; it was on a plot of land adjacent to the mobile home in which we were currently living. The house was finished in January, 1993. We settled in, thinking it would be a chance to rebuild our lives as well. It was a bittersweet moment when Junior gave me a gift that he and Adam bought before Adam became ill. It was a beautiful

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plaque with the word “Welcome” on it. They had found it while browsing through a local store and thought I would like it. I hung it outside on the wall right beside our front door. We also found many other items Adam had left behind that brought back memories of joy and sadness.

Still, “moving on” proved to be much harder than even Henry or I could have imagined. Henry set aside Adam’s coat as though one day he would come back for it. I put his eyeglasses away with the silly notion that he would return one day and need them. We were both delusional. Eventually, reason returned and I faced the reality that he was truly gone.

I cannot tell you how many times we longed to see Adam and hear his voice again. Sometimes when the wind calmly blew up against us, we imagined that it was our son’s caress. Anytime there was a strange noise in the house, or a cabinet door that opened on its own, we wondered if it was his spirit letting us know he was still with us.

One day, I was especially lonely for Adam. I asked the Lord to let me see him again and hear his voice. That night, when I went to sleep, my son appeared to me in my dream. He told me that he was happy and that he was safe in God’s arms. I cannot put into words the comfort that this brought me. I was still in agony over losing Adam, but at least my mind was at ease.

One morning shortly after that, Henry asked me to ride downtown with him, just to get out of the house for a while. I went into my bedroom to pick out a dress

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to wear. As I pushed back the clothes in the closet, I noticed a red dress I used to wear when visiting Adam at St. Jude. It reminded me of when he lay dying in the ICU. It seemed as though whenever I wore that dress to the hospital, we would always receive bad news about his condition. I had never been a superstitious person, but now I began to believe that this red dress was bringing me bad luck. I took the dress out of the closet and carried it down the hall toward the back door. On my way I passed Henry, who was sitting on the sofa in the den. "What are you doing with that dress?" he asked.

"I am throwing it away!" I answered, without breaking my stride.

"Why are you throwing a nice dress like that away?"

"Because this dress is a jinx! Every time I wore it when Adam was in the ICU, something bad happened! He always seemed to get worse."

Henry looked at me, clearly shocked. "That's superstition, and it's all in your mind. There's nothing wrong with that dress! And it looks nice on you." He sounded truly concerned as he added, "That dress has nothing to do with Adam, or any other bad luck we may have!"

I knew he was right. That dress was not a jinx. It had nothing to do with what happened to Adam. After all, it was just a dress. I took it back to our bedroom and hung it in the closet. I could not believe how silly I was acting. I needed to pull it together.

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Several months later, Randall was still carrying a lot of grief and pain inside. His personality started to change. Whenever we shopped for clothes, he would pick out clothes like Adam had worn; the same color and style. Whenever he selected his choice of food or toys, he would try to select Adam's favorite food and the same type of toys Adam liked. He would literally say, "Adam likes this." He even had to have the same style shoes Adam wore. Then he would try to mimic Adam's walk and act just like him. It was as if he wanted to become Adam. I asked him what he was doing. He said that if he could bring Adam back, he thought it would ease our pain. Seeing my young son taking on the burden of our grief, as well as his own, tore my heart in two. His trauma was not limited to home, either. He often came home from school upset because he had gotten into a fight with other children, bullies, who taunted him and said cruel things about his brother dying.

"Some of the children at school just don't seem to care about anybody," he said one day. He looked so terribly sad. "You know, Mom, they don't even respect the dead." But then he cracked a smile, indicating how tough he was, and remarked, "They just don't know me, Mom. They don't even know who I am."

I did not know who he was, either. His obsession with becoming Adam, coupled with his "prediction" that he was next to die, had seriously begun to disturb me. Henry and I decided it was time to seek professional help. We found a counselor we felt comfortable with and took Randall to see him. It seemed to help, at least for a while.

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A couple of months passed. I went to the grocery store one afternoon, unaware of how downhearted I looked until I paid the cashier for my groceries. When she gave me my change, she looked at me and asked, "What's wrong? You look as though you just lost your best friend."

"No, I haven't lost my best friend, but a few months ago I lost a son," I replied matter-of-factly. The cashier muttered a stunned, "I'm sorry" as I hurried out of the store. Sometimes I felt as though I was living in some other world. I'd find myself staring off into space, and walking through my life like a zombie. For a long time, I held back my tears, trying to be strong for my family. Then, one morning, while everyone was in the living room, I went into the bathroom and closed the door so no one could hear me. I curled up in a ball on the floor and cried and cried. After a while, I began to feel relieved, as though the pressure had lifted. I realized this was the first time I had allowed myself to really let it all out. I dried my tears and waited until the redness had cleared from my eyes. Then I got up off the floor and walked into the living room, where my family was sitting around watching television. They never knew how much pressure I had felt, or how relieved I finally was.

Ms. Marian Cocke was the host of the Elvis Presley Memorial Dinner Charity Event. Prior to Elvis' death, she had been friend to both him and his nurse. She was also a founding board member of the Memphis Chapter of the Make- A- Wish Foundation; all her work was voluntary.

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On June 5, 1993, she arranged for our family to attend the Stanley NFL Retirement Weekend presented by the Make-a-Wish Foundation. At the baseball game, we met and were photographed with some cast members of a soap opera, and members from the NFL teams autographed photos for us.

On August 14, Ms. Cocke invited us to be special guests at the Fifth Annual Elvis Presley Memorial Dinner Charity Event, which was held at the Peabody Hotel in Memphis. Celebrities and high profile guests from all over the United States would be in attendance, with all proceeds going to the Make-A-Wish Foundation. She had made sure those proceeds were specifically designated for our boys. We all had a wonderful time. Henry Sr. was asked to speak, and he made sure to thank everyone for their contributions, and showed his gratitude for the wishes that the Make-A-Wish Foundation was granting our sons.

We loved Adam and continued to miss him terribly, but with our attention now on our other children, the pain slowly began to subside. We avoided the bad memories of St. Jude by taking Carl and Junior to Dr. Curtis Patton, a local pediatrician. He conducted their regular checkups and gave Junior his IV of gamma globulin.

After a few months, however, Dr. Ribeiro suggested that we bring the boys back to St. Jude for a follow-up visit. After he had finished examining them, he advised us to continue taking Junior and Carl to Dr. Patton's for their regular check-ups. He said he would write or call us when it was time to bring the boys back

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to St. Jude. When we told him that Carl, our youngest son, was about to begin Head Start, Dr. Ribeiro had his secretary write a letter to inform Carl's teachers that his platelet count was low and he was therefore prone to severe bleeding. That way they would know how to react if there was an emergency. In September of 1993, Carl started school. As an added precaution, he was required to wear a helmet. Dr. Ribeiro did not want to risk his getting a head injury that, given his low platelet count, could turn out to be fatal.

On March 22, 1994, our family received a letter from the National Executive Secretary of St. Jude that read:

We are enclosing a photograph of the silver dedication plaque, which has been erected in the hospital in memory of Adam McNutt. The plaque has been placed on one of our wooden display boards on the Plaza Level of The Danny Thomas Research Towers, board number nine, row ten, down. We hope that you will have an opportunity to visit soon and see the plaque. We appreciate the continuing interest and concern of so many from St. Jude Children Research Hospital.

Sincerely,

Mrs. Sandra V. Lewis

The plaque read:

IN LOVING MEMORY of OUR PRECIOUS SON,
ADAM McNUTT

SEPTEMBER 19, 1980 - APRIL 14, 1992.

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GOD LOVING CHILD THAT WAS HERE FOR A
SHORT TIME

McNUTT FAMILY - WYNNE, ARKANSAS

Chapter 21

Junior's Vision

It was 1994, about two years since Adam's death. We had all moved on as best we could, trying to focus on our blessings. At fifteen, Junior appeared to be doing well. He had not been hospitalized for quite some time, and his prognosis was good. He was in the eighth grade and already learning to drive.

One day, as I was sitting at the dining room table going through a few outstanding bills, Junior came into the room and sat down next to me.

"Mom, I have someone I admire," he said matter-of-factly. "She is a nice, quiet, and intelligent girl and I would like to take her out on a date. I don't want to date those wild, loud girls, all I'll get from them is a hard time." He smiled. "Even though some of them do have an eye for me. Anyway, I'm going to ask this girl if I can go to her house and take her to a movie."

I just sat there, speechless. I'd had no idea that all these girls were interested in Junior.

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"You know, Mom," he continued, "I really do like talking to her on the telephone and at school. Of course, she doesn't know how I really feel about her. But one day soon, I will tell her."

As I listened to Junior talk, I felt my mouth curling into a proud smile. I realized that my little boy was growing up and turning into a man. After our conversation, I noticed that Junior could not wait to go to school each day. He so looked forward to seeing the girl and, hopefully, getting the chance to ask her out. The flame of romance was lit.

Junior often talked about the stupid things he and Adam had done in the past. One of the stunts he reminded me of was when Adam drank an old woman's snuff. "Mama, do you remember when you took us with you to the beauty salon? You gave Laverne some money to buy us drinks and something to eat at the store, but Adam couldn't wait. There was an old woman in the beauty salon, waiting to get her hair done, and as she waited, she spit snuff into an empty Coca Cola can. Adam discovered the can and thought he had found a can of Coke someone left behind. He knew you would not approve of him drinking someone else's coke, so he quickly turned the can up to his mouth and took a big swallow. Before he had time to really taste it, he went for the second swallow. Wasn't he surprised when he discovered it wasn't Coke! Remember, he got really sick? He slowly placed the Coke can back down and hoped that no one had seen him, but of course we all had." Junior burst out laughing as he remembered the look on his little brother's face. "When Laverne came back from the store with the food and drinks, Adam was

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too sick to eat. He couldn't walk back home either. You had to carry him, remember? He kept vomiting all the way home." Junior laughed again. "When Dad found out about it, he said, 'Good for you, Adam! You done it again, didn't you! Only this time you finally met your match. Ha! Ha!' Dad was having a great time teasing him. He said, 'I bet that snuff will slow your curiosity down, especially after someone done spit it out in a can.' We laughed all day about it, remember, Mom? Dad had warned us all about doing stupid things, especially Adam. But I guess, once again, Adam wanted to follow his curiosity." I nodded my head, chuckling along with Junior. It was so nice to be able to reminisce about the good times we shared with Adam, rather than those awful last days.

Laverne was now seventeen and growing up to be a beautiful young lady. She was a senior in high school, and had a job as a cashier at a local grocery store. She worked hard, saved her money, and eventually bought herself a new car. When I first saw her stick the key in the ignition, all I could think was that it seemed like only yesterday when she was toddler, sticking a key into an electrical socket. Now she was all grown up, and her interest in guys was growing as well. The problem was, every time she looked for a decent young man, she found herself mixed up with a "Casanova". Most of them were lazy, without jobs or goals, and while they appeared to ride in on a great white horse, it usually turned out to be nothing more than a jackass.

Junior loved to tease her about her choice of boyfriends.

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"One day, when those guys get off their high horses, they're going to use you for their donkey," he'd say, laughing. "They are going to ride your back for everything they need. They have no jobs or cars. The only thing they have is you. You will have to be the one to support them."

"No! Not a word you said is true!" she shouted. "I am not going to have anybody in my life like that! I may date them for a while, but one day I am going to find the man of my dreams, and he will have a real job and a very good car."

"Why don't you let him find you?" Junior asked.

They continued to argue with each other. It seemed to be their favorite pastime.

One evening, after Junior had returned home from school, one of his teachers called to tell me about the large knot under his arm. He had revealed it to her during class that morning. I thanked her and slowly hung up the phone. As Junior walked passed me, I told him about the teacher's call; I then asked him to raise his shirt and show me.

"How long has it been there?" I asked.

"Only a few days," he replied.

"Why didn't you tell me or your dad about it?"

"I wanted to keep it a secret. You and Dad have gone through enough problems with Adam and I didn't want to bring you any more bad news."

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“Junior, we have to know about it. If it’s something serious we need to know the cause. Does it hurt?”

“Yes, when I move my arm in a certain way, it does.”

“Well, we’ll have to take you to a doctor to find out what’s going on. Have you been playing rough at school?”

“No.” he replied, “Sometimes I wrestle with some of the boys at school. They don’t play that rough, though.”

I somehow doubted that. I knew how much he wanted to play like other children.

After taking a look at the knot, I immediately called St. Jude and made an appointment. The first thing they did was draw blood, and when the lab work came back it showed that it was infected. Junior had to be admitted in the hospital and given antibiotics and IV gamma globulin. After a couple of weeks of treatment, he was finally released.

It was early December, 1994. Henry had time off from work and we were preparing for the holidays. One day, Junior got a severe nosebleed. We tried pinching his nose to stop the bleeding, but it did not work. Then Henry washed a piece of salt pork and firmly packed it in his nose. This procedure seemed to work for a while, but although the bleeding gradually stopped, it would soon start back up.

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We had little choice other than to drive back out to St. Jude. On our way to Memphis, we stopped to get gas.

Suddenly Junior blurted out, "I am tired of this bleeding! Whenever I think I'm all right something else goes wrong, and I am tired of it."

I turned to look at him in the backseat; he looked worn out. "I know that you are upset and tired," I said gently. "After all, you've been in and out of the hospital since you were a year old. You can't give up, Junior. We love you. You are very important to us, and we certainly are not giving up on you. Just try to hang in there, okay?"

By the time we reached the hospital, the bleeding was out of control. A doctor who worked with Dr. Ribeiro examined Junior, and drew blood for analysis. She discovered that Junior once again had a blood infection and his blood count was low. He was admitted right away and brought to a room on the sixth floor. I went with them to the room while Henry stayed with Carl in the waiting area on the first floor. Henry told the doctor that he was concerned about Junior's medical problem and wanted him to be transferred to another hospital for a second opinion. When the doctor refused to transfer him, Henry became extremely upset. He explained to her that since Adam's death, it has been very difficult to bring his other children to St. Jude's.

As he was talking to her, Carl fainted in his arms. The doctor and Henry were stunned. The physician managed to wake Carl so she could examine him, and quickly discovered that he had a fever. When the blood

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test she ordered showed a very low blood count, she immediately had him admitted. He was also placed in a room on the sixth floor. I had been upstairs with Junior during all of this, and knew nothing about it. When I saw my youngest son being wheeled in the room next door to my oldest, I stared in utter disbelief.

I knew Henry needed to return home for work, but if anything qualified as an emergency, this did. I imagined us having to leave Junior “in charge” of keeping an eye on Carl. I had begun to feel that old sensation that this was more than I could handle.

In the end, Henry called work and was able get a couple more days off so he could stay at the hospital. A few days later he went home, and I stayed behind to watch over the boys. Carl was treated for his fever, then given a blood transfusion for his low blood count. He was there for a week, then Henry returned to the hospital to take him home.

Junior, who was still being treated with medication, had to stay in the hospital for another week, and I stayed with him. When my mother found out what had happened, she was very upset that I’d had to attend to our two boys alone. When Henry came to pick Carl up, she came with him. She stayed with Junior so I could rest. After two weeks he too was released, and we considered ourselves lucky that we’d be able to spend the holidays at home, not in the hospital.

One night shortly after Christmas, Junior awakened to use the toilet. Before he flushed, he saw blood in his urine and asked me to come and see. I reasoned that it was due to the medication he was

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taking and that maybe he wasn't drinking enough fluids. However, after a couple of days of increased fluids, his urine still did not clear.

On December 29, 1994, Henry and I took him back to St. Jude, and once again, he was admitted. He was given a blood and platelet transfusion and treated with antibiotics for infections. With the blood transfusion, his blood count increased and his urine cleared. When after a few hours blood was again visible in his urine, the doctor ordered an x-ray to try to determine the cause.

The doctors scrutinized the x-rays but could not figure it out. Another doctor was brought in from Le Bonheur Children's Hospital and he x-rayed Junior as well. He was able to see that one of his kidneys was blocked and not draining properly. A catheter was ordered to help drain the urine. Once the urine was completely drained, it started to become clear.

The same day, a social worker came by Junior's room to check on him. I wasn't around at the time. Junior told her about the bleeding problem that he was having. He then asked her if the problem could be fixed.

Later, the social worker came by to inform me about Junior's medical condition. She then repeated to me what she had told Junior. "I'm afraid they can't fix it right now, but they will keep trying," she said, then added, "Sometimes a person's body is like a hole in a bucket. When it's a small hole, you can fix it for a while, but later, when the hole becomes too big, there's nothing to hold it together. You simply can't fix it anymore."

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“But why haven’t they found a cure?” I asked. “It’s been almost three years since Adam’s death.”

“One reason is that no one famous has it,” she answered.

“And why does someone famous have to have the illness before they can find a cure?”

The social worker replied, “It takes a lot of money and research to cure diseases. This means it takes a lot of media attention. The rich and famous have the money, and the ability to make others aware of their problem. This disease is very rare. We don’t even know anyone else who has it.”

I then told her how upset I was that she had told my fifteen-year old child that his problem could not be fixed. In other words, he could die. I did not want my son to hear that news, especially from a stranger. She looked at me, then, without another word, she left the room.

Later, when the doctor came by Junior’s room and took out the catheter, his urine once again had blood in it. I could not believe there was nothing they could do to help him.

New Year’s Day came and went, and Junior was still in the hospital. It was now 1995. My mind wandered back again to the man that had held the hospital staff hostage for not taking proper care of his child. I was still thinking about it when an unsuspecting social worker walked in the room.

“Now, I can understand how that man must have felt,” I said angrily. “Something like this can make a

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person become violent. There are times when I feel like doing the exact same thing, even though I may get shot and killed!"

Not certain what I was talking about, she glanced up at me to see if I had gone insane. After checking on Junior and without saying a word, she left the room.

The second week of February, I took Junior to school to gather his things from his locker. As we walked down the hall, we ran into the assistant principal. "How has Junior been doing?" he asked.

"Not very well," I replied.

He looked Junior up and down. "I have noticed that he lost a few pounds."

"Yes, he has lost weight. His appetite hasn't been very good lately."

"Well, I hope he'll be all right."

"Thank you," I said, then Junior and I continued down the hall. We gathered his belongings and left the building.

Over the next few days, Junior continued to bleed. Henry and I became extremely concerned. We tried to figure out what else could we do to solve this problem. This was beginning to feel like too much to handle. During this time, Carl had an appointment to see Dr. Patton for a checkup. We took Junior with us, and while we were there we asked Dr. Patton what he thought about the bleeding. He was concerned as well. "Have the doctors at St. Jude tried to stop it?" he asked.

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"Yes, but nothing works," I said, then decided to ask him about what we had been told at St. Jude. "Do you know anyone else who has lost blood in their urine?"

"Yes, for various reasons," he replied.

"How long did it last?" Henry asked.

"On some occasions, I've known it to last for as long as three months or longer. What are the doctors at St. Jude planning to do about it?"

"For now, he's on a lot of medicine, and he constantly needs platelets. We're going back there tomorrow morning for a checkup."

"Well, I wish you the best of luck," Dr. Patton said gently, "and hope they can do something about it soon."

"Thank you," I replied.

Fortunately, on this trip to the doctor, Carl was doing fine.

The next day we took Junior back to St. Jude, and once again he had to be admitted due to the bleeding. He did his best to be strong during all of this, but the burden he carried was heavy. He knew his body was too weak for his spirit.

"I don't want to get so sick that I look like some of the children here," he said, adding, "I know it could be the strong medicine that makes them appear that way." I knew he was thinking about how drastically Adam had changed at the end of her life.

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"Yes," I said emphatically, "I'm sure that strong medicine has a lot to do with it."

Henry had to return home for work the next day, so I stayed with Junior at the hospital. I spent that night in the parents' room. The next day, Junior wrote a letter to the girl he admired. We mailed it to her, along with his picture.

To make easier for both of us, I had persuaded the hospital to give us a wheelchair so I could push him around the hospital. We went outdoors to get a little fresh air. The air was cool and crisp and fragrant with the scent of freshly cut grass. Fat lazy clouds decorated the sky, but there was no forecast of rain. I thoroughly enjoyed this precious time with my son; it was as if we were trapped in a dimensionless time warp.

After our stroll, I took Junior back to his room. He waited until he knew Henry would be home for work, then he called him. "I am tired of all this bleeding. If God is going to heal me, He needs to go ahead and do it, because I'm really worn out."

"Try and hang in there, son," Henry told him. "I know you must be tired, but your mother and I are still praying for you, and for Carl. We're hoping that God will turn things around and you'll be alright."

After their conversation, Junior seemed to have a better attitude about his situation.

The bleeding episodes grew more severe, however. The doctor ordered more platelet transfusions in an effort to stop it, and the staff kept constant watch over Junior so they could check his progress. After a few

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days, Dr. Ribeiro determined Junior was doing well enough to go home for a few days and spend time with the family.

On this particular trip, I noticed something new about my son. Many people visiting the hospital brought toys and other gifts for the children being treated there. It made their hospitalization a little easier to bear. Junior also received gifts, and we gave him money for the gift shop. He saved whatever was given to him, and, when he felt well enough, he would go down to the gift shop. But instead of buying things for himself, he bought toys and other items for his brothers and sisters. He could hardly wait to go home to see the rest of the family and give them their gifts! He loved watching the expressions of joy on their faces as he handed them out.

We will always be thankful that he was able to see Laverne on her 18th birthday, and that he was there to see her go to the senior prom. This meant a lot to her.

On the morning he was due to go back to the hospital, Junior was awakened by the sunlight shining through his bedroom window. I was doing laundry and getting his things together when he came into the kitchen, still rubbing the sleep from his eyes. As I made his breakfast, he told me about a dream he'd had the night before. While he was asleep, he felt as though his spirit had left his body in preparation to be carried away to heaven.

"I could see my body still lying on the bed," he said. "Then, I saw an old man... I really didn't know who he was, but I believe he was your dad! He told me to go back to my family. 'They love you and they need you', he

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said. Then my spirit returned back to my body." Junior had the strangest look on his face as he told his story. "Some other strange things have been happening to me, too," he added. "Like sometimes I'm awakened by talking in my sleep." He chuckled. "I never did this before."

I was puzzled and a little scared by what he told me. "Well, I don't know what's causing you to do those things now, but it sounds a little spooky to me."

We took Carl along with us when we drove Junior to the hospital, but left the rest of the children with my mother. As Henry drove to Memphis, Junior talked about Adam and the good days they'd had together; how they shared secrets and had a lot of fun with each other.

We finally reached St. Jude. As we walked into the building, Junior smiled and said, "Mamma, when I get admitted in the hospital, I want Room 606."

"Why do you want Room 606?" I asked, suspiciously.

"I just want that room," he replied.

I asked, "But what if someone is already in there?"

"We'll tell them to move into another room," he laughed.

After a few minutes, the nurse came and took him to be admitted. "Put me in Room 606," he told her.

"Okay. If I you're lucky," the nurse replied, then checked on the computer to see if the room was

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available. Unfortunately, she discovered that someone else already had that room. "I am sorry, Junior," she said, "but you'll have to take another room." She checked again and that she would be able to assign him to Room 605, right across the hall.

As we approached the room, it suddenly dawned on me why it was so significant. It was the room where Adam underwent his transplant, and later died. When I said this to Junior, he laughed and nodded his head.

"How did you figure that out? I still want that room," he said, teasingly.

Once again, Henry had to leave for home; he couldn't miss any more work. Carl stayed at the hospital with Junior and me, and the three of us had a great time together. We talked about the time when Junior was very young and had grossly enlarged lymph nodes, and how the doctors had talked about amputating his toes and fingers. During our conversation, he called for a nurse. He knew there was a book at the hospital with pictures of him in it. One picture showed him with a big happy smile, even with the enlarged lymph node. Another showed his toes and fingers, so swollen and discolored that they indeed looked like they might need to be amputated.

"You were strong and you kept your faith in God," I reminded him, "And because of that, you soon became well. I am hoping and praying that you will be all right this time, too."

"Yes, I guess I was really strong back then. Mom, I still have faith in God, but I just don't feel strong like I once did. I mean, my body doesn't feel as strong." He

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thought for a moment, then smiled to let me know he was clowning around. "Maybe it's because I am getting older."

I smiled back, but I was crying inside. "You may not feel strong physically, but inside, you are very strong, despite all the things you have gone through."

Junior nodded, but he had that strange look on his face again. It was as if he knew something I didn't.

Early Friday morning, Henry came back to the hospital to spend some time with Junior. He sat down in a chair beside his son's bed and the two began talking as if it were just another normal day. It was the best way to keep everyone's spirits up.

It also gave me a much needed break, as I was exhausted from sitting up all night. I picked up Carl and was about to head to the parents' room, which was adjoining Junior's, to lie down when I heard Junior say to Henry, "Go and spend some time with Mamma. She sat up all night watching over me and barely had sleep. I'm fine."

Henry obeyed, and after we'd all had a little rest, we returned to the room to help Junior take a bath. We dressed him in a clean hospital gown, just as breakfast was being brought into the room. Henry and I noticed he was pushing his food around; he didn't seem to have much of an appetite. Henry and I tried to encourage him to eat his food.

"But I'm not hungry," he said, with his usual bright smile. "I'll eat it later."

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“Well, your dad and I need to go to the laundromat and wash some clothes so we will have something to wear. We’re taking Carl with us.”

“Go ahead. I’ll be all right, but don’t stay too long.”

I don’t know if it was his words, “don’t stay too long”, but while we were at the laundromat, I suddenly got this nervous feeling in my gut. I called Junior’s room to make sure he was okay.

“Are you and Dad finished with the clothes?” he asked.

“Almost,” I answered.

“Okay, but when you’re finished, you need to come right back to the hospital. I’ve been nauseous and vomiting.”

When I told Henry what Junior had said, he became alarmed too. We finished the clothes as quickly as we could and rushed back to the hospital.

After dropping Carl off in the parents’ room, when headed to Junior’s room. He was sitting up in the bed with a hospital pan in his lap.

“I’m glad that you came back,” he said with a weak smile, “because I’m starting to feel sick.”

I called for a nurse to check on him, then sat on the edge of his bed and caressed his neck and shoulders. Henry sat in a chair on his opposite side of the bed. After a few minutes, Junior lay down to rest.

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"Gwen, you should go to the parents' room and get some rest," Henry suggested, "I'll watch Junior."

I peeked through the large window that separated the parents' room from Junior's, comforted by the sight of Carl playing with his toys.

"Yes, Mamma, go over there with Carl and rest. I'll be all right. Dad's here with me." I nodded, then went to be with Carl and to rest. From the parents' room, I could hear Henry and Junior on the other side of the glass talking, laughing, and singing a few hymns. Later on, I began to feel uneasy, so I went back to Junior's room to see how things were going.

"I knew you couldn't stay over there," Henry said, and they both laughed.

"Well, I came over here to be sure that Junior is still doing okay."

"All you had to do was look through that large window," Henry teased.

"Yes," I said curtly, but I was smiling too. "But I can't hear everything through the window." I went and sat at the edge of his bed.

"Then turn on the microphone in the room!" Junior said, laughing.

But just a few minutes later, Junior began complaining of a severe headache. Henry called the nurse to examine him.

"Where does your head hurt?" she asked.

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"Mostly over here," he said, rubbing the back of his head and neck. Then, suddenly, his nose started to bleed. We gave him a tissue and he blew out large clots of blood that looked like lumps of beef or pork liver. Henry and I stood by, helpless, as the headache got worse and worse. No tears fell from his eyes, but he held the back of his head, screaming and crying for relief. I held his head in my hands, trying to keep the throbbing pain from attacking him again. I was horrified when all of a sudden, I felt the skin in the back of his head rise as though something was trying to come out of it. We would later learn that it was blood clots, trying to pass through his veins.

The nurse left the room and called a doctor. By this time, Dr. Ribeiro was no longer with St. Jude, and we waited to see who they would send. In the meantime, the pains kept coming, one after another. Junior was completely worn out.

Things rapidly began to spin out of control. Henry showed me places on Junior's body - mostly his back and his tongue - where large, blood-filled blisters were hanging from his skin like ticks on a dog. Junior had shown his dad earlier, but didn't want me to know about it. Now, as I looked at his back and tongue, I almost passed out. Even worse, bluish-black bruises had begun to appear all over his entire back and other parts of his body. My son looked as though he had been beaten with a baseball bat. I felt the panic overtaking me. My heart felt like it was just going to stop. I did my best to keep calm for Junior's sake, but after a few minutes I had to leave the room. As I went next door to check on Carl, I thought, "Please God, not again!"

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From the window of the parents' room, I saw a doctor going in to see Junior. I pulled it together, then I walked around to Junior's room to see what was happening. Once he'd examined Junior, the doctor said he would order medication to ease the pain. He left the room, and a couple of minutes later, a male nurse came in with a pill.

"This pill will make you drowsy and help you to rest." He handed the pill and a cup of water to Junior, then waited until he swallowed it.

I walked over to look through the window at Carl, who was still in the parents' room. The door of the room was open, so I could see into the hall. There, standing at the nurses' desk, was one of my sisters and her husband. I told Henry, and he went to go speak to them. A moment later, he returned to the room, along with my brother-in-law.

"Junior, your aunt, and uncle are here," Henry said, then, under his breath, he thanked God that Junior was still alert.

Junior turned toward me and said, "Mom, I can feel the medicine working now; I'm getting drowsy. I'm going to lie flat on my back and put both of my hands behind my head and neck, just in case I start to have some more pains. That way I can put pressure on it."

I waited for him to get settled, then I left the room and went down the hall to greet my sister. The two of us went into the parents' room, where Carl was still resting quietly. We sat and talked for a while, my eyes darting constantly through the large window to check on Junior as he slept. After a while, she asked me

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to show her the ladies' room so she could freshen up, then she, Carl and I went back to the room to wait.

When we got there, I looked through the window again, but this time what I saw chilled me to the bone. Henry and my brother-in-law were standing by Junior's bed. Henry was shaking Junior and calling his name, but Junior did not respond. Then, suddenly, hands still tucked behind his head, he moved his left arm and leg; however, he did not seem to be aware of anything or anyone around him. Something was very wrong.

I rushed into the room, went to his bed, and began shaking him roughly. "Junior! Junior!" I yelled, trying desperately to wake him, but he was nonresponsive. I knew he was dying, but I refused to believe it. I kept yelling out his name and telling him to breathe, but all I heard was a few gurgling sounds. I took this as a sign that he had heard me, so I continued to shake him. I could only hope he felt the pressure and the warmth of my hands and would come back to life.

The nurses heard all the commotion and rushed in to see what was going on. They took one look at Junior and knew he was in trouble. One nurse tried to revive him, while another left the room to get a doctor. Within minutes several doctors rushed into the room, but Junior's heart had already stopped. They tried to revive him manually, but it took a defibrillator to get his heart beating again. Then they put him on a stretcher and rushed him across the hall to the ICU, where he was given heart medicine and attached a monitor. Once his heart was stable, at least for the moment, they checked his brain functions. They discovered that there was no

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activity at all. A scan of his head revealed that every part of his brain had filled with blood. At 4:30 a.m., April 28, 1995, the doctors officially pronounced our eldest son dead.

I stood there in a daze, unable to process what was happening. Suddenly, I remembered Carl, alone in the parents' room; he had probably watched his brother die. When I got to the room to get him, I found two nurses already with him. One was wiping tears from his eyes, and the other was trying to comfort him. Somehow, I remembered to thank them for their help; then I reached for Carl's hand and took him to the waiting room outside the ICU. I held him on my lap and cuddled him, but I knew he was terrified by what had just happened to his older brother.

As soon as they heard the news, several of my other brothers and sisters showed up at the hospital to support us. As with Adam's death, news traveled quickly through our community, and our pastor and his wife also drove to Memphis as soon as they found out. Even in our agony, Henry and I were grateful that our family and friends were there.

We stayed at the hospital for a little over three hours, waiting for the undertaker to come and pick up Junior's body. It was a calm, sunny day as they loaded him into the hearse for the trip back to Wynn. When we arrived home, Adrian and Randall were outdoors playing, unaware of the sad news. They ran up to our vehicle, happy that we were home and assuming that Junior was with us. As we were getting out, then looked inside and asked, "Where is Junior?"

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When Henry told them Junior had passed away, they were completely stunned. Although they knew that Junior was very ill, it seemed inconceivable that he was gone. Henry and I consoled them as best we could, and later that day, more friends and family came to our home to console us. Everyone was trying to console the inconsolable, make sense of something unspeakable.

Later that afternoon, Henry and I went shopping for clothes to wear to the funeral. Henry also picked out a nice dark blue suit, a white shirt, and a matching tie for Junior to be laid to rest in. Henry made it a point to match the suit he'd bought for himself with the one for Junior.

Once again, Henry assigned himself the most painful task. The next day, he drove to the funeral home, where he chose a beautiful light blue casket. Henry insisted that it had to look like it was perfect for a grownup. Even though Henry Junior was only fifteen when he died, he had already grown to be a young man of six feet, two inches tall.

The funeral service was held on Wednesday, May 3, 1995 at 1:00 p.m. Many people came, young, and old, black and white, to pay their respects.

During the service, Carl and Randall went to see Junior lying in rest. Laverne, Adrian, and I wanted to remember him the way he was before he became so ill, so we chose not to view the body.

Henry Junior was buried at Paradise Garden Cemetery, in a plot close to Adam. The grief we felt was unspeakable. We would miss our beautiful boy so terribly - his smile, the funny things he said and did, and

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his spirit of giving and helping others. I knew I would never forget the day when I was very low on money and needed gas to put in my vehicle. Junior was in the car with me and heard me talking about it. He thought I was not paying attention, but I saw him slyly slip a few dollars into my purse. I “caught” him as he was pulling his hand out. “What are you doing in my purse?”

He laughed, and said, “Oh, Mom. I didn’t want you to see me do that. I wanted you to look in your purse, see the money, and think that God had sent His angel to earth to bless you.”

He said it like he said so many other things - like a joke - but I could see the truth of my son’s generous heart. Another time, one of his aunts needed money to pay a utility bill. He heard her talking about the struggle she was having. He reached in his pocket and pulled out all of his money - about fifteen dollars. He handed it to her and told her to put it toward her bill. She was stunned to see such a young boy with such kindness, and although she refused to take his money, she was very proud of her nephew.

Junior’s generosity extended far beyond money. He had always enjoyed helping people when they were ill, even when he was not feeling his best. I will always keep him in my memory and my heart. To this day, we all long to see him. Moreover, we take comfort in knowing he is with God, and that God has strengthened us and given us the power to carry on. We will always love our son, Henry Lee McNutt, Jr., and remember how he always held onto his faith, even when he was facing

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illness and death. We found this anonymous quote says it best:

When I was small, I was sick back then

But my troubles did not win

*My trials and snares came hard, it presses like the
wind*

But, I held on, I did not bend

Then the Lord came for me, and I did not defend

*Because He said I will see you all again - Unknown
author*

Chapter 22

Hawaii

In August of 1995, about three-and-a-half months after Junior's death, our family was invited to the seventh annual Elvis Presley Memorial Dinner at the Peabody Hotel in Memphis. Many people were there from different parts of the country. Henry was again asked to be one of the speakers for the Make -A -Wish Foundation.

Henry thanked the friends of the late Elvis Presley for making the wishes come true for our children. He expressed how our family missed our son,

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Henry Junior, and wished that he could have been there with us.

Those at the benefit knew that eleven-year-old Randall suffered from the same disease that had taken his brothers. When the Make-A-Wish Foundation asked Randall if he had a wish, he nodded enthusiastically. Randall wished to go to Hawaii.

In November of that year, the Make-A-Wish Foundation flew our family to Honolulu. At the end of our long flight, we got off the plane to find volunteers from the Kenui Aloha Lei greeters there to meet us. The kids were so excited when they saw the sign that said, "Welcome McNutt Family". Then the music began and the greeters did their hula dance. A young Hawaiian man took our luggage and escorted us to the transportation area, where a rental car was waiting.

Make-A-Wish had arranged for us to stay at The Outrigger Village and planned a complete itinerary of activities. We wanted for nothing. That trip to Hawaii was a much needed taste of paradise. In the coming months we would need to hang on to those happy memories, for our faith was about to be tested again.

We returned from Hawaii in the early morning hours of November 28, 1995. It was Carl's seventh birthday. That evening, we gave him a birthday party and invited friends and relatives to help us celebrate. By nightfall, he was not feeling well. We thought it was just all the excitement of our trip, followed by a long flight and the party. But the next day he was still sick, so I took him to the clinic to be examined by Dr. Patton. Soon after we arrived, they called Carl to the back to be

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weighed. I walked with him to the examination area, but when he went to step onto the scale, Carl became very weak and fell to the floor. For a moment the nurse and I stared in terror at his small body lying limply across the scale, then she sprang into action. As she picked him up and called for Dr. Patton, I saw the color of death spreading across my son's face.

Hearing the urgency in the nurse's voice, Dr. Patton and his wife Susan, who is an Advanced Nurse Practitioner, rushed into the room. When they saw Carl's stiff body lying in the nurse's arms, they knew there was no time to lose. Dr. Patton grabbed my son, then he and Susan ran to Baptist Memorial Hospital, which was right across the street from the clinic. I just stood there in stunned silence, not knowing what to do.

Several minutes later, someone called from the hospital and told me where to find Carl. When I got to the hospital, I was frightened. I did not know what to expect. When I entered Carl's room, he was lying in a hospital bed with an IV in his arm. He was getting a blood transfusion. Susan Patton was standing beside his bed.

"Mrs. McNutt," she said kindly, "try not to worry about Carl. I am going to stay right here in the room with him until I know this little fellow is going to be all right."

Shortly thereafter, Dr. Patton returned to the room to check Carl's blood count; then, as soon as he was stable, he was transported to Le Bonheur Children's Hospital. Carl stayed there for several days, until he was better. God had spared us the heartbreak of losing

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another child, for now anyway, and we thanked Him endlessly. Maintaining our faith in our family, and in God, had become our number one priority.

The next few months were uneventful, and before we knew it, April had arrived. Laverne, our oldest child, turned twenty and moved out on her own. The following Sunday was Easter, and Randall and Adrian wanted to attend church. Mostly they wanted to take part in the Easter egg hunt and the other activities that were going on at church. Carl wanted to go too, but I was nervous. He'd had a fever a couple of days before, and I was afraid he would become ill during church.

"But I feel all right now, Mom," he pleaded.

Still, I wanted to be sure that he did not have a blood infection. I went to the medicine cabinet and got a thermometer. He had no fever, and he looked well. "Okay, I surrender!" I said, throwing up my hands. "You may go to church! Now hurry up and get dressed. I will call your aunt and ask her to come by to pick you all up." Smiling, he bounded to his room and I said a silent prayer that nothing serious would happen to my baby.

The children dressed swiftly, as children always do when they are headed somewhere fun. A few minutes later, my sister arrived to get them, and they were laughing as they piled into her car. But only two-and-a-half hours later, she was back, and Carl was with her.

"He said he didn't feel well, so I brought him home," she said simply, trying not to worry me. Adrian and Randall were still at the church, she said, they had wanted to stay until all the activities were over.

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My sister headed back to the church, and I took Carl into the house and grabbed my thermometer. I sighed with relief when I saw that he did not have a fever. He laid on the couch and I put the T.V. on for him. *He seems to be doing fine*, I thought as I watched him drift off to sleep. *Maybe he is just tired.*

A little while later, I woke him up and sent him to his bedroom, checking on him every few minutes. He was sleeping peacefully, and I left the room to finish my chores. My sister's house was within walking distance of ours, so I stepped out the front door to see if Randall and Adrian were playing in her yard. When I did not see them, I went back in the house and closed the door. That's when I heard Carl stumbling down the hallway, trying to find me. As I walked toward him, I saw him fall in front of the doorway to the den. He was down on his hands and knees, and struggling desperately to get up. The front of his shirt was soaked with blood; it was flowing freely from his nose, creating a small puddle at his feet. It all happened so fast. I rushed toward him, but just as I got there he fell flat on the floor and became silent. I could not get him to respond. Terrified, I scooped him up in my arms, screaming "No! No! No, God! Not my baby!" From the depths of my being, I begged the Lord to spare my youngest child.

I knew we needed to get Carl help immediately. Henry had worked the overnight shift and was sleeping soundly in our bedroom. With Carl in my arms, I staggered down the hallway, still pleading with God. I was so loud that I startled Henry awake. He quickly turned on the light to see Carl lying in my arms, covered

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in blood. Petrified, he threw his clothes on so fast he forgot his shoes.

Holding Carl close to my bosom, I continued to call his name over and over again as I followed Henry out to the car. Finally, with a very weak voice, he answered. With tears rolling down my face, I thanked God that my son was still alive. We got into our vehicle, Henry in the driver's seat, me in the passenger seat, and Carl in my arms. As we sped down the road, we saw Randall and Adrian playing in my sister's front yard. Henry screeched to a halt and opened the door. They ran over and saw the fear in our eyes, then Carl lying in my lap, covered with blood. Without saying a word, they jumped in the car. As we pulled off, Henry realized he had no shoes on his feet. He rushed back to the house, got a pair of shoes, and put them on as he drove away. In the meantime, I kept talking to Carl, trying to keep him conscious until we got to the hospital. After finally getting Carl into the building and then settled in a room, the children and I noticed that Henry had his shoes on the wrong feet. The children snickered. I was amused, but too worried about Carl to laugh.

The nurses immediately put an IV in Carl so they could give him a blood transfusion and antibiotics. This had become such a normal routine, the nurse knew exactly what to do. He stayed in the hospital in Memphis until he was well enough to be released.

Chapter 23

The Officer

After so many trials and tribulations, a happy milestone came our way. On July 4, 1996, Henry and I celebrated our twentieth wedding anniversary. We invited our family and friends to help celebrate this wonderful occasion. By this time, Henry's mother had been disabled by a severe stroke and my mother had been diagnosed with cancer, so we felt very blessed that they were there to share the day. We were also so grateful to have our four wonderful children - Laverne, Randall, Adrian, and Carl - with us. The day was all about love, not just the love between me and Henry, but the love we shared with all our family and friends.

In August of 1996, we took Carl to St Jude for a follow-up appointment. Henry and I hated the idea of returning to that hospital. While we knew that they had done everything they could to save our boys, the painful memories were so difficult to face. On the other hand, we didn't feel we had much of a choice. The doctors and nurses at St. Jude knew our family, and we were afraid to make a change when Carl had been so ill. There was one change over which we had no control: Dr. Ribeiro had left St. Jude, and Dr. Wang had returned. He would now be Carl's physician.

When we arrived, we were surprised to find that a big portion of the hospital where Junior and Adam stayed had been remodeled. It was oddly comforting to

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know that we did not have to go back to the same old hospital rooms and clinic.

By March of 1997, Carl's condition had gotten worse. We had to make trips to St. Jude every few weeks. Dr. Wang gave us detailed instructions on how to decrease Carl's exposure to potential sources of infections at school. We also had to supervise him closely at home for evidence of bleeding.

I was also facing another loss. By May, my mother's cancer had taken a turn for the worse, and she passed away on the sixth, just a few days before Mother's Day. Over the years she had often kept watch over Carl and our other children during the many emergencies, and they had grown to love her and respect her deeply. She had become a very important part of our family and her death - especially after losing two of their brothers - was a terrible blow to the children.

It was late one evening in October of 1997. I had spent most of the day on housework, then making dinner, getting things ready for Carl's doctor appointment, and getting Randall and Adrian prepared for school the next day. By 8:30, I went to lay down on my bed, utterly exhausted. The children, however, were full of energy and continued to play - loudly - in the den. As much as I hated to spoil their fun, around 10 o'clock I got up and firmly declared that it was time for bed. Without argument, Randall and Adrian went to their rooms. A few minutes later, Carl climbed into my bed, lay down beside me and went to sleep.

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Early the next morning, I awoke to the feel of Carl's small hands on my shoulders, shaking me. "Mom," he said calmly, "my nose is bleeding." Still groggy, I got up and turned on the light. Carl's skin was very pale. I pinched his nose in an attempt to staunch the bleeding, but it only worked for a few minutes. When I realized the bleeding was not going to stop, I became alarmed. I quickly got myself and Carl ready, then I went to the kitchen and got a piece of salt pork, washed away the salt, and packed it in his nose. This time it did not help. He continued to bleed.

Realizing the severity of the situation, I called Henry at work. He'd been on the overnight shift again and it was almost time for him to get off. I told him about the nosebleed and that I couldn't manage it alone. We decided I would head straight for the plant. When I got there, Henry was waiting for me at the entrance. He walked up to the car and peered through the window to see how bad it was. He took one look at Carl and quickly climbed into the back seat, trying to control the bleeding. I was shocked when he then told me to drive to Memphis. Like many men, Henry had always been wary of female drivers, particularly during an emergency. I didn't stop to question him, though; I just sped out of the parking lot and onto the highway in the direction of Memphis. I drove faster and faster, terrified that Carl was losing so much blood. While speeding through Crawfordville, Arkansas, about thirty-miles from home, a policeman pulled out behind us and turned on his siren and flashing lights. I pulled over to the side of the road and stopped. He walked up to our vehicle and asked for my driver's license. As I handed it

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to him, he noticed Henry and Carl in the back seat. "What is the problem?" he asked, "Why are you speeding?"

"My son is very sick. He is a patient at St. Jude's Research Hospital in Memphis." For some reason I felt the need to explain further. I thought that maybe by telling him a little about Carl's medical history he would let us go. I was so nervous as I spoke that I was nearly out of breath. "He has a disease called Fanconi Anemia, and he could easily die from the bleeding."

The policeman took a closer look and saw the blood dripping from Carl's nose. His skin was very pale. "What is your name?" the policeman asked my son.

"Carl," came the weak reply.

"How old are you?"

"Eight," Carl replied, grasping onto the side of the hospital bedpan that was in his lap. A towel hung around his neck, resting on his chest to keep the blood from staining his clothes. Henry held Carl's head up as he spoke.

The policeman then turned his attention back to me and proceeded to ask what seemed like an endless litany of questions about Carl's illness, then about my driving over the speed limit. When I had answered them, he looked back to Henry and repeated the same questions, needlessly postponing the medical attention Carl needed. I started to become very agitated. Carl could die right in the back seat of our car because of this man's ridiculous interrogation. By now he had to be aware of how ill this little eight-year-old boy was.

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“Please, Officer! Let us go so that we can get help for him. He is getting extremely weak and I am afraid he will die if we don’t get him to a hospital soon!” I pleaded with the policeman, but he just ignored me. A couple of times, I was tempted to drive off and leave him standing there. The only thing that stopped me was my fear that he would call for backup and they would start shooting at our vehicle! Henry decided to ask the police officer to drive us to the nearest hospital in his car; maybe then Carl would get help before his condition worsened. The policeman refused, but finally, he went back to his car and called in to Crittenden County for an emergency medical vehicle.

Nearly an hour had passed before the paramedics arrived. By that time, Carl’s nose had nearly quit bleeding. Severely depleted of blood, he was extremely pale and weak and tormented by a severe headache. I knew that the extreme loss of blood in such a short time could send him into shock.

The paramedics tended to Carl, then put him on a stretcher and into the ambulance. I climbed in with him, and Henry walked back to our car so he could follow us to the hospital. I nearly lost it when the policeman wasted even more time by carrying on a conversation with the paramedics before we left. He showed no concern for Carl’s condition whatsoever.

The policeman then walked back to our car and instructed Henry to stick to the speed limit, rather than the speed of the ambulance. Eventually, the paramedics pulled onto the highway and headed for St. Jude. Henry

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followed, but at the much slower speed. Needless to say, we were soon out of his sight.

When the paramedics radioed ahead to St Jude, they responded that we should take Carl to Le Bonheur Hospital instead; they felt it was better equipped for such an emergency. Of course, there was no way to let Henry know. Following the edict from the police officer, he had lost us in the heavy traffic, then headed for St. Jude. I cannot imagine the level of frustration and anger he felt when a nurse informed him that Carl had been taken to Le Bonheur.

By the time the paramedics reached the hospital, Carl was unconscious. He was immediately rushed into the emergency room, but it seemed like an eternity before the doctors did anything to revive him.

When Henry finally found us, he rushed to Carl's bedside and began speaking to him, saying anything to keep him alert. Unfortunately, it did not work. Carl was too tired and weak to stay conscious. After examining Carl, the doctor told us that he was extremely ill and needed to have surgery on his head. We knew we had no choice. For the next several hours, Henry and I sat in the waiting room. When the surgeon finally emerged from the room, we knew the news was not good. It was something about the tilt of his head and the expression on his face.

"While we were doing surgery on the right side of his head; we saw that the left side of his brain was badly damaged. I noticed that his brain stem was partially herniated." Then he added, "We lost him on the

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operation table... but we shocked him and brought him back. He is still in critical condition, though.”

As I listened to him speaking, I felt like someone was squeezing my heart tighter and tighter. I could see the agony on Henry’s face as we joined hands and prayed to God that He would keep Carl alive and let him come home with us once again.

Carl slipped into a coma and was put on a life support, then moved to a room in the ICU. Henry and I stood beside his bed, listening to the awful sounds of the machines that were keeping him alive. We will remember those sounds for the rest of our lives. We looked around the ICU. Some children were fighting to live, others did not even know they were still in this world. Parents were sitting beside their child’s bed with tears in their eyes, just like us, hoping and praying that their son or daughter would get well and return home.

A few hours later, a doctor came to the waiting room and asked us to sign a paper that gave them permission not to revive Carl if his heart stopped again. Henry and I refused to sign the papers. A family nurse practitioner and several nurses, along with Mrs. Martha Rieman from St. Jude, came to support us. The nurse practitioner brought a beautiful quilt to keep him warm while he was in this cold room.

By this time, we had called Laverne back home and told her what was happening. A few hours later, she arrived with Randall and Adrian.

Carl’s head was now extremely swollen. Laverne fainted when she saw him, but Randall refused to give up; he kept the faith no matter how bad things

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appeared. He encouraged Adrian and the rest of us to believe that Carl would be all right. The social worker, Chris Sinnock, asked us if we wanted them to take handprint; it would be for us to keep in case he died.

"No, thank you," we told her. We wanted to keep our expectations high. We believed that Carl was coming home alive.

The attending physician disagreed. "He probably will die," he told us. "His brain is badly damaged. Even if he lives, he will probably remain in a coma and will have to be on a life support machine."

We heard the words, but we refused to panic. Even though Carl was just a young child, Henry and I knew that he was a fighter, and we believed and trusted God.

A week passed with no new developments. Then one day, Henry and I walked into the room to hear that one of the nurses had seen Carl's left hand move. The news increased our faith immensely.

The next day, Henry and I were sitting beside Carl's bed when he moved his right hand. The attending nurse saw this as well, and reported it to the doctor when he came by to check on him.

"Carl moved his left hand yesterday," she said happily, "and his right hand today."

In a matter-of-fact tone, the doctor replied, "It was only a reflex."

We refused to accept his diagnosis.

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Carl had been getting antibiotics through his IV; despite this, however, he developed a high fever. The nurse put a cold towel on his forehead and an ice pack under both of his arms to help bring it down. A few minutes later, two of my sisters came into the room, and the nurse left us alone for a while. My sisters caressed Carl and talked to him. I moved the ice pack from under his right arm to make it easier for them to touch his arm and hand, but I forgot to move the one from under his left arm. Carl pointed his index finger of his right hand toward the left. Both of my sisters saw it.

“Look, Gwen!” One said excitedly, “Look at the way he is moving his finger!”

“He must want you to come here!” said the other sister, “He must want you to move the other ice pack!”

“Let’s go tell the nurse.” With smiles of joy on their faces, they left Carl’s bedside and quickly caught the attention of one of the nurses on the floor.

The nurse came, held Carl’s hand, and told him to squeeze. Carl followed her command, slightly gripping her fingers in a squeezing motion. Again, she reported this to the doctor. The doctor came in to examine Carl for himself. After telling Carl to squeeze his hand numerous times and getting no reaction, the doctor once again determined that it was nothing more than a reflex.

“I’ll keep checking on him to see if he moves it again,” he said curtly, then he left the room.

A couple of days later, Carl’s doctor came to the ICU room to examine him. He took Carl’s hand and

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asked him to squeeze his. This time Carl responded, squeezing ever so slightly. The physician realized that he had gained a little strength, but was sure he would never be the same. Carl was plagued with a high fever, and the doctor tried other types of antibiotics to get rid of it. Unfortunately, nothing worked. The doctor assumed the fever was there because of the damage to his brain. But within a few more days, Carl had recovered enough to be taken off life support. A tracheostomy tube was put in his throat to help him breathe, and a gastric feeding tube was inserted into his stomach.

On November 28, 1997, his ninth birthday, he was moved to another part of the hospital, called the TCU. In this area, a patient cannot be on life support. Nurses in this section of the hospital train parents on how to take care of their ill child when they leave the hospital.

While Carl lay in his hospital bed in TCU, a young female doctor and an older nurse came in to take charge of Carl. Both the nurse and the doctor thought Carl looked closer to death than life. The nurse thought there was no way he would ever move his extremities, or be aware of his surroundings. She told us not to have high expectations. She even suggested that when a child is this ill, their parents are often so anxious to see him or her get better; that they see things that are not really happening. In other words, signs of Carl's progress were just our wishful thinking.

The next morning, before dawn, the nurse came into the room and turned Carl's face toward Henry. She

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tucked a pillow between his legs to keep them from rubbing together and making sores. Several pillows were used to help make him comfortable. Henry awoke and looked across the room at Carl. He saw Carl open his right eye; it seemed like he was looking straight at his father. Henry got up off the cot, walked over to Carl, and stood beside the bed, looking at him.

“Carl,” he said calmly, “are you looking at me? If you are, wink your eye.” Carl slowly winked his right eye. At first, Henry thought it was an illusion, so he tried something different. “Carl, if you really did hear me, move your head.” Carl slowly moved his head. Henry held Carl’s hand and said, “If you can squeeze my hand, do it”. With a light grip, he squeezed Henry’s hand. Then Henry said, “I knew that you were looking at me! I knew that God was going to let you come back!” Then he said to Carl, “When your doctor comes back into the room, you should do something to show her that you are getting better, and maybe they will work harder to get you well enough to go home. Do that for me Carl, please?” Henry begged. Then Carl slightly nodded his head, moved his hand, and gave a big yawn. This was the most activity we had seen since his surgery, and Henry was determined to get proof for the doctors. He told Carl to yawn again, and he did. Excited, Henry repeatedly told him to yawn. Each time, Carl did. In disbelief, Henry quickly found the nurse in charge and told her what had just happened. The nurse came into the room to see for herself. Henry showed her how well Carl was responding to him. He told her, “Hurry and get the doctor, so she can witness Carl responding!”

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The nurse left and got the doctor. In a few minutes, they both returned to the room.

The young doctor came in, rubbing her eyes. "Now that you woke me up so early in the morning, it had better be good!" She walked to Carl's bedside, took his hand in hers, and told him to squeeze. Carl lightly squeezed her hand, then yawned. "Carl, yawn!" she repeatedly said to him. He did it repeatedly, as many times as he was instructed. The nurse told him to hold up one finger, two fingers, and then three. Carl followed her commands. "Yes!" the doctor laughed with enthusiasm, "We are getting somewhere! I am sure he can understand every word. Now his nurse and I can write this down in our report to show proof that he is getting better." She left the room with a big smile and a happy heart.

What a relief! A doctor had finally witnessed Carl's responses.

Back home in Wynne, the Strong Tower Church planned a benefit for Carl.

The Wynne Progress Newspaper printed an article about it in the December 5th edition. It Read:

A TEAM EFFORT (Carl McNutt Benefit Set)

A benefit program for the family of Carl McNutt had been set for 3 p.m., Sunday, Dec.14 at Strong Tower Church, 336 West Davis St., in Wynne. McNutt, 8 is critically ill at Le Bonheur Hospital at Memphis. McNutt suffers from Fanconi and Wiskott Aldrich disease, a genetic blood disorder.

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Two of his brothers, Henry Jr. and Adam, already have died from the disease and another brother, Randall, also suffers from the ailment. Donations to help offset the family's medical bills also may be made to the First National Bank, in the name of Carl McNutt. The Wynne High School Bible Club has donated \$500 to the fundraiser, and students at Wynne Junior High have prepared a baked food drive for the family.

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Chapter 24

Professional Support

During the holidays, our physician told us that Le Bonheur Hospital was out of the type of blood Carl needed. They sought other places in the city of Memphis for his blood type, but they were also out. Around this time of year, people do not donate blood as often. Henry and I were very upset about this news. We knew Carl was fighting various infections and he frequently needed blood and platelets in order to survive.

Henry called and spoke with Mrs. Diane Jones, the owner of Halstead Industries, where he worked. She often supported The America Red Cross and Life Blood by having blood drives at her plant. When she got the news that Carl needed blood and the hospital was out, she called the manager at Red Cross and Life Blood in

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Memphis, Tennessee, and offered to conduct a blood drive. Once they collected Carl's blood type, she immediately had several pints sent to Le Bonheur Hospital. The rest was sent to Life Blood in Memphis to keep in storage for Carl. Other blood types were sent to help other patients.

The Thanksgiving holiday and Carl's birthday had passed. He had received many gifts, which our friends and family brought to his hospital room. Now Christmas was around the corner, and they had started to bring cards and gifts for that holiday as well. I took all of the cards and taped them on his wall in the form of a large Christmas tree. I hoped that whenever he awakened fully and was aware of everything around him, he would see the big tree on his wall, and all the unopened gifts. We hoped and prayed he would feel our love and hear our prayers to keep fighting and get well.

One night during Christmas week, Henry stayed with Carl in his room. Early morning, around dawn, the neurosurgeon's colleague came into the room. When he saw Carl's condition, he was very distressed about how much he was suffering. He walked over to Carl's bed and stuck a needle in the base of his neck to drain some of the fluid collecting there, putting pressure on his brain. When he finished, he turned to Henry, a solemn look on his face. Then suddenly, he snapped. "Look at him! Just take one good look at him! How would you like to lie there in a hospital bed unable to move or anything? Does he appear to be having fun to you?"

Henry, who had been lying on a hospital cot, immediately shot up and stared angrily back at the

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doctor. "Are you blaming us for him being sick? My baby still has life! And his mother and I are doing everything possible to help him to get better! What do you want us to do? Kill him? Or, perhaps let you kill him and put him out of misery?"

The doctor just stood there and stared at Henry for a second or two, then he swiftly turned and left the room. Later on, Henry came and joined me in the lobby. He told me what the doctor had said to him. We couldn't figure out what had caused him to speak so harshly, but we were very upset about it. Why couldn't the doctor see how desperately we wanted to turn things around? We were so proud of Randall and Adrian, who had put their time and patience into caring for their brother. We hoped, prayed, and physically worked very hard with Carl to help him regain his strength and get better.

Due to the extreme swelling, the doctors had to remove a portion of Carl's skull. For three full months, the pressure had remained too severe to put it back. Finally, though, Carl started to show real signs of physical improvement. Most of the swelling went down, and the neurosurgeon decided to replace the piece of skull back to protect his brain. At the same time, a shunt was inserted into the brain to drain the excessive fluid and relieve pressure.

A few days later, the neurosurgeon discovered that the shunt was not working properly. He would have to perform another surgery to remove it. After a few consecutive surgeries, Carl's health improved. He was responding to stimuli and was soon transferred to a regular floor in the hospital, where he could start

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physical therapy. The physical therapist ordered a leg brace, a wheelchair, and a standing board to aid him in regaining his strength. After a few weeks on the regular floor, he was transferred to St. Jude's Research Hospital so his regular physician could keep watch over him and make sure his blood count remained stable.

The next day, I was sitting by Carl's bed when I got a call from Henry. While we were talking, Carl started frowning terribly, as though something was irritating him. I thought he wanted to talk to his father, and was upset that he had no voice to speak. I put the phone to his ears, and when he heard Henry's voice on the other end, he started shaking his head rapidly, as if irritated. I did not understand what was happening.

A couple of days later, Henry brought Adrian, and Randall came to the hospital to visit their brother. During their visit, Carl started frowning and shaking his head again, almost like Stevie Wonder does when he is behind the piano singing. We knew that something was going wrong, and although Henry and I examined him, we could not figure it out. About thirty minutes later, we discovered that he was having severe muscle cramps. We called for the doctor, who put him on medication to ease the pain.

After three weeks of physical therapy, he started gaining more strength in his jaws, mouth, and in his right arm. He gained enough strength in his arms to bring his hand up to his head. When he first began to respond, he could not even scratch his nose. Now he was trying to speak.

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One day the neurosurgeon came to the room and re-examined Carl. When he finished with the examination, he pointed towards Henry and me and asked Carl, "Do you know who these people are?"

"My mom and dad," he mouthed.

"What are their names?" the doctor asked.

"Henry and Gwen," he mouthed. He was mute, but we could read his lips.

The neurosurgeon said with amazement, "His brain is still functioning very well. He seems to understand everything he knew before he got really sick. What a miracle!" He added. "I didn't think he would come back as strong as he has!"

A few days later, a woman who worked with special care patients realized that Carl needed a different method of physical therapy than what was offered at St. Jude. She ordered him to be sent to a rehabilitation hospital in Memphis that treated mainly older patients. But she was not completely satisfied with that therapy either, so she later sent him to Jonesboro, Arkansas to the Health South Rehabilitation Hospital. The physical therapy instructor worked very hard with Carl, helping him gain as much strength as possible. Still, they noticed that his behavior was not normal for a nine-year-old child, but was more like that of a three-year-old. The doctor told us that people who have had severe brain damage or brain surgery sometimes have shifts in personality or attitude.

A person who usually has a very good attitude or behavior may change to the opposite, and vice versa.

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After staying a few months in Jonesboro, Carl became stronger and his health seemed to be improving dramatically. Eventually he was released to go home with us. A home health nurse was ordered to be available for whenever we needed.

That first day home with Carl was a great experience. It was like bringing home a newborn child. He always had a big beautiful smile and waved his hand whenever someone came into his room. He did the funny things a small child would do. He brought joy back into our lives just by having him home again. One day we took him in the living room so he could see all the birthday and Christmas gifts we had saved for him, then we helped him unwrap them. When he saw the multitude of gifts, he was very excited. His favorite gift was a balloon. He loved batting at it with his unparalyzed hand (his left hand was still paralyzed). Yet, he was still different from the Carl we knew before the surgery. It almost seemed as if we had lost the Carl that I gave birth to; that he had been replaced with another child. I supposed God knew that we could not bear his death so suddenly after our other boys, so He spared Carl's life a little longer. Whatever the reason, we were very grateful just to have him back.

Carl brought joy to many people by waving, winking, and throwing kisses. But then, as if someone had flipped a switch in his brain, he would throw a tantrum for no reason. It was extremely frustrating, but we realized that our child was still very ill, and we needed to be patient with him. We worked hard to help him gain both his strength and knowledge. Our work was not in vain. After the entire trauma Carl had

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encountered, he was well enough to be home. He was still diagnosed with Fanconi anemia, and Wiskott - Aldrich syndrome, but we had him home. He had to be closely monitored by his doctor. This meant we had to take him back and forth to the clinic to have his blood count checked on a regular basis, but we did not mind if this was the cost of having him with us.

One day, during his routine visit to St. Jude, the physicians saw that something was wrong and readmitted him. I stayed in the hospital room with him and slept on a cot a couple of feet from his bed.

Later that night, I was awakened by a noise. I got up to check if Carl was dry and sleeping comfortably, but when I looked at him, I saw his face was wet with tears. "What's wrong?" I asked.

"That woman slapped me," he said. I looked around in the room, but saw no one. "The nurse," he mouthed without uttering a sound. Within a few minutes, a nurse opened the door to his room. The minute she walked through the door Carl pointed at her and said, "You slapped me!" She rushed to his bedside with a sly smile and held his finger, hoping to make him shut up and stop pointing, but Carl continued to say, "You slapped me! You slapped me!" He was very upset and tears were still rolling down his face.

"You must have had a bad dream, because I would never do a thing like that to you, Carl. Shhh! Hush!" She said as she attempted to cover his mouth with her hand.

But he did not stop; he repeatedly told what had happened to him. I did not know whether Carl had had a

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bad dream or if it really happened. I could only try and protect him. I felt the anger rushing through me.

"Well, if you did a terrible thing like that to him, I would appreciate it if you never do it again! I will report it to the head nurse and have your behind up and out of here!"

"I never slapped him!" she exclaimed, clearly very upset; then she turned and rushed out of the room.

There was a male nurse sitting in a chair behind the nurse's desk. I saw them talking and looking at me through the large window of Carl's room. She looked angry and upset, so I assumed she'd told him about the incident. I did not mention another word to her about it, but felt the need to watch my son a little more closely. After a few days, Henry switched places with me, so I could spend time at home and rest.

While staying at the hospital, Henry had problems with the same nurse I had confronted about slapping Carl. He had explained to her that when he or I were around, we would like to suction out Carl's tracheotomy tube. We had been trained to do so, and we knew that pushing the tube down too far could severely irritate his throat. We were also concerned about possible bleeding, to which he was prone. Other nurses didn't have a problem with us wanting to do it; in fact, they welcomed it.

This nurse, on the other hand, continued to insist that she should be the one to suction him at all times. At first, Henry backed off and gave her the suction catheter, but just as we feared, she severely irritated Carl's throat. He doubled up in bed and gagged for

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breath as blood flowed from his trach. Clearly upset, Henry immediately took the catheter out of her hands. Instead of apologizing to him—or to Carl—she angrily rushed out of the room.

When I returned to the hospital, I asked the head nurse to have the woman removed. I explained that Henry and I felt very uneasy around her.

“I will do just that,” she said. “I’ll have her moved as soon as possible.”

Maybe we were being paranoid or a little overprotective, but it didn’t matter. Carl was our only priority. When the nurse found out that I had reported her to the head nurse, she was livid. She also wasn’t shy about letting us know it. One day I was tending to Carl when I was startled by the sound of a harsh voice.

“You don’t ever have to worry about me taking care of him anymore!” she snapped. She had opened the door to the room and stuck her head in the doorway. “I won’t assist him ever again!” Then she slammed the door to the room, leaving me quite shocked. Did she think I’d be sad to hear that she wouldn’t be around Carl anymore? It was actually the best news I had heard in a while. It was bad enough sitting up all night worrying about my baby, at least I no longer had to worry that a nurse might harm him.

For a few days, the nurse did not come back to the room. Thank heaven, I thought, I finally got her out of here for good!

But then she gradually started coming around again, sometimes bringing Tylenol to Carl’s room and

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leaving it for Henry or me to give to him. Other times, she gave it to him herself, even though we were there. I wondered if the head nurse had given her permission to do this. This woman knew I did not want her in Carl's room ever again, yet for some reason, I could not keep her away. I even asked some of the other hospital employees about her, hoping to put my mind at ease. Most workers said they did not know a lot about her, but as far as they knew, she was a very nice, very lonely woman. She did not have anyone to go home to, just her cats and dogs. I tried to ignore her and just focus on Carl.

For some unknown reason, he had started to have a lot of trouble with his feeding tube, more problems than even we could have anticipated. The surgical doctor had to replace it two or three times a day. His liver had also stopped functioning normally. For some unknown reason, everything that passed from him - his tears, saliva, urine and stool - was yellow.

Despite this, we were determined to keep up our faith, which we did through prayer and reading scriptures out of the Bible. I read to Carl every morning, noon, and night. We hugged, kissed, and said "I love you" to each other constantly. I knew he was God's child and that one day, sooner or later, God would come for him and take him to His Kingdom. On that day, our baby's troubles would be over.

One day, Henry and I were standing by Carl's bedside when all of a sudden he looked up toward the ceiling and pointed. Henry and I looked up in the

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direction he was pointing and tried to figure out what he wanted us to see. Then he said, "Heaven."

"What about Heaven?" Henry said, trying to keep his voice steady.

"I am going there." Carl told us

Shocked at his statement, I managed a deep breath and a smile. "Are you leaving us now?"

He smiled back and shook his head. "No, but when I do go, I am going to Heaven."

Even though I did not want to accept the fact that he would someday leave us to go rest in God's arms, I felt Carl had prepared himself and was now warning us to be prepared; that sometime soon, his soul would rest in Heaven.

A few days later, Carl was able to come home, but by October, 1998, he had to be admitted again. He had developed a blood infection and other severe medical issues. Doctor Wang ordered a chest x-ray, which was normally a benign procedure. The technician administered the necessary medication, then began the scan. She managed to get some shots of his lungs when she noticed that Carl was going into distress. She stopped the scan and was about to call the doctors when he suddenly flat-lined. The tech immediately called out and the doctors had to come in to help revive him.

"I don't know what caused this reaction," Dr. Wang told us, "but I don't think it was the medicine." Later, when the doctor looked at the x-rays he saw something on Carl's lung but could not figure out what it

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was. The doctor then ordered another scan, despite the earlier incident.

Later on, Dr. Wang and several other physicians determined that the spot they saw on Carl's lungs appeared to be some type of fungus. They knew it was very serious, so they immediately administered Amphotericin-B through Carl's IV.

We were hopeful that the IV medicine would clear it up, but the fungi only continued to grow. The day before Thanksgiving, Dr. Wang and the family nurse practitioner told us that we needed to have a conference about Carl's condition. When we had all settled into the conference room, Dr. Wang announced that he was releasing Carl from the hospital so he could be home with us for Thanksgiving. At first, Henry and I were overjoyed that we would all be able to spend the holiday at home. Then we saw the expressions on their faces.

"This could be his last time to go home," The nurse practitioner said. She was looking me directly in the eyes, trying to see if I was absorbing every word. "Take him home and take some nice pictures of him."

After the conference, Henry and I silently made our way back to Carl's room. I could not let it settle in my mind what she had just told us, that this could be Carl's last time to go home with us. I wanted to believe that she meant we would not be able to take him home again soon.

In the meantime, we were grateful that he would be spending that night in his own bed. We had a wonderful Thanksgiving and, even better, Carl was still

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home to celebrate his tenth birthday. It was November 28, 1998. We threw him a nice birthday party, with family and friends who were only too happy to show their love for our baby. A couple of days later, Carl was readmitted to St. Jude so he could resume his treatment of Amphotericin-B via IV, and other medications. But despite everything the doctors did, his condition continued to worsen.

By the latter part of January 1999, Carl was very ill. He did not want to play or bat balloons. He quit waving, winking or throwing kisses to people. When I talked to him or called his name, he seemed lost, unable to pinpoint where my voice was coming from. Yet he still could feel the pressure of my lips when I kissed him, and with the little strength he had, he'd kiss me back. Then his blood pressure started to drop and he was taken by stretcher to the intensive care unit, where he was treated with stronger medicine and could be watched very closely by the physician. I was afraid that I was losing him, but hoped that God would continue to provide His strength. Sure enough, Carl soon recovered enough to be taken back to a regular room.

That same day, Dr. Wang came in, bringing with him the scent of the soap he'd just used to scrub his hands. As I sat at Carl's bedside, he spoke to me about Carl's condition, specifically the amount of money being spent on his care. Money was the least of my concerns. I would have sold my home, or any other thing of value, if it would help save my baby's life. I knew the hospital had been established by charity to help sick children; I also knew that our insurance was paying a large portion of Carl's bill, so I did not worry.

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Later that night, I saw the nurse who Carl claimed had slapped him, along with his current nurse, leave the nurses' station and walk down the hall together. Suddenly, all these thoughts began racing through my mind. I remembered how the doctor had accused Henry of prolonging Carl's suffering; how the nurse had irritated Carl's trach tube; and how Dr. Wang had brought up the subject of money. What if the nurses were plotting to kill Carl because he was not dying fast enough? I watched as they returned to the nurses' station, then the new nurse came into the room and injected medication in Carl's IV bag.

"What is that you're putting in his IV bag?" I asked.

"Some medicine to help his stomach and other infections," she said.

Deep in my heart, I believed she was lying, but I felt helpless to do anything about it. After all, I didn't have any evidence of wrongdoing, only my suspicion, which may have been because I was not ready to accept the fact that Carl was dying.

Early the next morning, before daylight, Carl became very ill. The nurses pushed his hospital bed back to the ICU, while I called Henry and told him about Carl's condition. He gathered Adrian, Randall, and Laverne, and they headed for the hospital. We continued to petition God to perform a miracle and let Carl be all right. But we knew God wanted to deliver Carl from his illness and pains in His own way. On January 28, 1999, our baby's suffering was over and he went to rest in God's arms.

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Henry and I drove back home and arranged for Carl's funeral. It was held on Tuesday, February 2, 1999 at 12:00 p.m. His casket was white, the same as Adam's, but without the gold trim. Many people came to the funeral. Family, friends, and relatives, including Dr. Patton and Mrs. Martha Rieman, were there to support us in our grief.

Randall knew I had made it a rule never to view the bodies of my children. So I was surprised when during the ceremony, he turned to me and said, "You should go see Carl, Mamma."

"Why?" I wanted to know.

"I just think you should walk up to his casket and see him."

Whatever Randall's reason, I knew it came from his heart. I knew Henry was preparing himself to go up in view the body, and from somewhere inside, I gathered up my strength. "Henry," I whispered as I leaned into him, "I am going up there with you to see Carl."

He took me by the arm and, followed by Laverne, Adrian, and Randall, we walked up to view Carl's body. Laverne was not strong enough to take the pain of seeing her youngest brother in the casket. She fainted and had to be carried out of the building by her friends. After the funeral was over, Carl was buried at Paradise Garden Cemetery, next to his older brothers, Adam Lewis and Henry Lee, Jr.

Carl was a child after God's own heart, and baptized at an early age. In spite of his sickness, for

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most of his life he was an energetic and happy child who never gave up the enjoyment of living his life to the fullest. Even after being confined to the hospital, he continued to bring joy to others by winking, waving, and throwing kisses. Carl was loved by many and will be remembered in a very special way. I will always miss his lovely smile, hugs, kisses; but most of all, I will miss his sweet voice calling my name and saying wonderful things, just to let me know that he will always be my baby and the youngest of the family. Yes, he was my precious baby, the last child that I gave birth to, and now he had been taken away. I knew I would always long to hold his warm body on my lap with my arms wrapped tightly around him, singing hymns and rocking him to sleep once again. He was like the family teddy bear; he was everyone's favorite. "Your stomach is my big fluffy pillow," he often said to his dad after having a cheerful and exhausting day outdoors with his brothers and sisters. When he was well enough, he would run at high speed, as fast as he could, down the hallway past the bedroom door where his father sat just to make him say, "What on earth just passed my door? Was it a bird or a rat? It went so fast I couldn't see what it was." Carl loved to see that look of amazement on Henry's face.

Carl, Randall, and Adrian were very close to each other, and Laverne was like their second mother. Henry Jr. and Adam had both been incredibly protective of Carl. We all love Carl very much and will always miss him beyond words.

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DEDICATION

God knew that you were suffering. The hills were hard to climb.

He gently closed those loving eyes and whispered, "Peace Be Thine".

The weary hours, the day of pain, the sleepless nights have passed.

The ever patient, worn-out frame, has found sweet rest at last! - Unknown

"My Brother and Me"

by Sandra K. Smith

My brothers and I were not here very long.

Just a moment's flash and it seems we were gone.

We played in the grass. We went to school.

We lived our lives by the golden rule.

We had faithful nurses and doctors, too,

But how to heal our bodies, they had no clue.

So we took a trip to a faraway land,

Where we joined a crew called the Christian band.

We love it here. There are no aches and pains.

Our robes are white and free of stains.

We laugh and play where it is bright as the sun.

The angels here have real "Carl" fun.

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*They lifted us high so that we could see,
That there is no better place, for my brothers and
me.*

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permission.*

In late March, after Carl's death, Henry and I donated Carl's supine and transfer board that we had purchase for him, to the Arkansas Children's Hospital in Little Rock. On April 10, 1999, we received a letter from the supervisor of child Life and Education Dept. It Read:

Dear Mr. McNutt,

On behalf of the children cared for here at Arkansas Children's Hospital, thank you so much for your generous contribution of a supine and transfer board for our special patients.

Arkansas Children's Hospital is the sixth largest children's hospital in the United States. Our Child Life and Education Department is designed to meet the emotional, social, developmental and educational need of children and adolescents. Because of friends like you, we are able to provide quality programs, which make the hospital less frightening and more comfortable for the thousands of families who come here to receive medical care.

Again, thank you for thinking of Arkansas Children's Hospital. Your kindness is greatly appreciated.

Most sincerely,

Gloriane Kabat, Supervisor

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Not long after we buried Carl, I began to reflect on our life.

Having learned several years ago that each of our four sons had either Fanconi Anemia, Wiskott-Aldrich, or both, our hope of seeing any of them grow up and have a normal life had become very dim.

The constant trips back and forth to the hospital in Memphis, the countless sleepless nights, had made me very tired and deeply depressed. At times, I felt I could not go on with my life. I became feeble-minded, and couldn't remember the simplest things. Even going to church became almost more than I could bear. The hymnals sung by the choir, and those long, hard, pleading prayers, depressed me even more.

It did not seem to matter how hard we tried, how much we hurt, or how often we prayed; our sons still kept getting sick and dying. Even though I tried to keep my faith and belief in God, I found it harder and harder to go inside a church. I felt that no matter how we lived our life, or how much I prayed, there was nothing we could do about it; it was God's will to take our boys.

Still, in the hours of my darkest despair, I often turned to the Bible, specifically the Book of Job. Job was a perfect and righteous man, yet he still faced trials and tribulations, to the point of losing everything. His own flesh, according to the scriptures, was afflicted with boils. I thought about how difficult life must have been for this poor man, over and over again. I believed in my heart that God had given both Henry and me the strength to bear the test of losing three sons. I also understood that my strength was nowhere near that of

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Job's. I found myself pulling farther away from the church. I guess Henry must have felt the same, because after a while, we both stopped going to church altogether. In fact, our lives did a complete one-eighty-degree turn, from clean-living Christians to a life of worldly pleasures. We started going out to the clubs, drinking alcohol, and using profane language. We disrespected God in ways we had never done before. I know now that we were trying to find answers and a little peace of mind about what was going on in our lives. We could not understand why our boys kept being taken. But no matter what we did, we found no answers, no peace of mind. Eventually, I realized that prayer was the only answer to finding the peace we so desperately needed. Through all our toils, I came to believe that God was still good to us. Henry and I had managed to stay together though all the adversities we faced. After twenty years of marriage and unspeakable agony, I could honestly say that we still had only love in hearts, love for each other, and love for our children.

"For we are saved by hope; but hopes that are seen is not hope: for what a man seeth, why doth he yet hope? But if we hope for that we see not, then do we with patience wait for it." (Roman 8: 24-25)

"Faith is the substance of things hoped for, the evidence of things not seen." (Hebrews: 1-11)

One definition of Prayer is, "A reverent petition made to God; A communion with God." I know it was our prayers, Henry's and mine, that kept us on the right path to maintaining our faith, and continue to do so to this day.

Chapter 25

Randall – The Last Survivor

When Randall was seven years old, an expert in rare blood diseases once told us that he had Fanconi anemia, the same blood disorder as Carl. Yet unlike his brothers, he had never been hospitalized, for neither Fanconi nor Wiskott-Aldrich syndrome, the other disorder that ran in our family. In 2001, seventeen-year-old Randall was in the eleventh grade and doing very well. His grades were good, and in May of 2002, he graduated from high school and was preparing to attend his first year of college. The last of our boys was now a man.

It had been five years since we lost our youngest son, Carl, and despite our daily burden of having lost him and our other two boys, life had become normal. I went back to work to help pay for our enormous bills, and Henry and I went about taking care of our home and our children. But most importantly, we begged God to please allow Randall, or “Randy”, as we called him, to stay here on this earth with us. I had hoped and prayed that our legacy of loss was finally over.

By the time he turned nineteen, I had begun to believe that he would not succumb to this awful disease..

In 2003, he applied and entered the University of Arkansas in Pine Bluff (UAPB), with a plan study

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engineering. He was also engaged to Kristie, a lovely young woman Kristie from McCrory, Arkansas, who he had met back in 2001. Kristie and Randy had even decided to attend college together. He was embarking on a normal, happy life, and I was sure the deadly legacy was indeed over.

Around the second weekend of October, Kristie's mother called to tell her that some relatives from out of town were in McCrory to visit. She was preparing a huge dinner for them and wanted Kristie to come home for the weekend. Randy went with her. After they had dinner and visited with the family, the two of them drove to our house in Wynne. Randy wanted to do his laundry before returning to school.

Randy was big and broad like his dad and stood about 6'2 inches tall, but he had such a warm and gentle smile. He was sweet-natured person like me, I used to joke, making sure Henry was around when I did so. When on that trip home he flashed that big beautiful smile, his older sister Laverne noticed that his gums were "drooping". It was the strangest thing. They were all red, raw, and swollen. They were hanging so low you could barely see his teeth! It was then that Kristie mentioned how Randy often became short of breath just from walking to class, and that lately he seemed to be tired all the time.

"At one point," she added, "his eyes were very red, and I could see the enlarged lymph nodes on his body. He also developed bad sores under his armpits."

Randy was so determined to finish out his freshmen year that he had hidden his illness from his

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dad and me. Now, we had to realize the truth: Randy had begun to exhibit the all-too-familiar symptoms of Fanconi anemia.

As he folded his freshly laundered clothes and placed them in his bag, Kristie and I tried to talk him into seeing a doctor. "No, Mommy!" he said, continuing to fold. "I have to go back to school. I've studied hard for the test tomorrow and I want to take it."

As he spoke, I was thinking, There are sixty miles between Wynne and St. Jude, where our other sons were treated, and later died. I have constantly hoped and prayed that we do not have to travel that long, dark and lonely road again with another sick child. We had driven that road almost every day, every year, for more than a decade. Along the way we often heard the sounds of rumbling trains and howling dogs off in the distance. We had learned every twist, turn, and bump of that lonely road of death. Now, standing here looking at Randy's drooping gums, I knew it was time to make that trip again.

"Did you hear me boy?" I blurted suddenly, "Go see a doctor!"

"Mom, I need to take my test!" he repeated, and I could hear the disappointment in his voice.

"Well, if you won't go on your own, I'll have your sister Adrian bring me your dad's shotgun and I'll take your legs right out from under you and take you myself."

He laughed as he replied, "Mom, listen to yourself. If you shoot my legs off that would be worse

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than swollen gums.” Then he saw the look on my face and held up his hands in surrender. “Okay, I’ll go. I know you’re just being a mom. I’m fine, but I’ll go, so, quit worrying.”

The next day, he went to the local doctor, who performed the routine blood work and a urine sample. There was blood in the urine, so the doctor sent him to a hospital in Memphis for further testing. Henry and I drove him there. Once we arrived, the doctors there admitted Randall into the hospital to perform more tests. When he was stable enough, we returned home for work. A couple of days later, Randy’s doctor wanted to perform a bone marrow biopsy, but Randy refused. Randy called me at work from his hospital room to tell me what was going on.

In the meantime, a member of the hospital staff decided to do a financial search, as they thought Randall did not have insurance. When indeed the search produced no insurance policies, the hospital ignored the fact that he was sick and bleeding, as well as his family history, and released him. However, since there was no one to pick him up, he was escorted across the street from the hospital and into another building. Around seven o’clock that evening, while on my break, I called Randy’s hospital room. When no one answered, I became very concerned and called his cell phone.

When he answered, I sighed with relief. “Why didn’t you answer the phone in your room?”

“Because they discharged me, Mom. When I asked the nurse if they could wait until tomorrow, because I had no way to get home, she said, ‘No, you

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have to be discharged now.' Then a nurse took me through a tunnel to another building, and right now, I'm sitting in some woman's office. I know you and dad are at work, but I need someone to pick me up. The woman said she's leaving to go home in about two hours."

In that instant, my young man became my little boy again, and he needed me. I told my supervisor that I needed to leave and headed to Memphis, which was a little more than an hour's drive. I arrived to find Randall limp and hunched over in the chair in the office. He appeared to be very weak.

As soon as we got home, he called his aunts and uncles and asked them to meet with him for a prayer. By ten o'clock that night, everyone had gathered in our home. Relatives from out of town went into prayer at the same time, in their own homes.

The next day, the bleeding in his urine was gone and he seemed stronger; however, he still had other medical issues, so we took him back to see our local doctor. From earlier blood work, he saw that Randy's red blood cells were very low. He also noticed abnormal cells that appeared to be cancerous. This time he sent Randy to the Methodist University Hospital, also in Memphis, Tennessee.

On October 14, 2003, Dr. Donna Przepiorka (or "Dr. P", as everyone called her) told Randall that he had Acute Myelogenous Leukemia (AML), and he was admitted into the hospital. She said AML happens in about nine percent of all Fanconi patients.

"If you hadn't come in when you did," she said, her words chilling us to the bone, "you probably would

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have been dead within a few days - no more than three weeks."

Days turned into weeks, and weeks turned into months. He needed chemotherapy, which had to be carefully administered. Too much could kill him; too little and he would certainly die. A bone marrow transplant from either a living donor or an umbilical cord stem cell was the only chance of a cure. This was also a frightening prospect for us. Bone marrow transplants were a common remedy for Fanconi patients; however, a similar procedure had resulted in Adam's death in 1992. We could only hope that the many advances in medicine since then, and the many prayers sent in his behalf, would lead to a different result for Randy.

There were only three hospitals in the U.S. known for transplants on Fanconi patients, and Dr. P recommended the Fanconi Anemia Comprehensive Care Program at Fairview-University Medical Center. It was affiliated with the University of Minnesota. They were pioneers in the field, and in 2000 had made headlines by performing the first umbilical cord blood transplant on a Fanconi patient. They had used genetic testing to ensure a perfect tissue match.

It was now January 2004, and Dr. P was in Randy's hospital room, making yet another pitch to us about the necessity of his getting the procedure. "Randall will likely die soon without a transplant," she said. "He has been in this small blue hospital room for over four months now, and we are past the ability to keep his condition under control." Then she added, "It's

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only by his own strength that he has been able to keep going, and finding a match for him is proving difficult. There are five million people on the marrow registry. Only eight percent of them are African-American. To make matters worse, his tissue type is extremely rare.”

After months of chemotherapy and other medications, and tired from all the testing, Randy said “If it’s my time, then it’s my time. I accept it.”

This tore my heart out. I did not want to hear or accept that this was happening to my last surviving son. On the evening of January 6, we got a call from Dr. Wagner in Minneapolis. He told us that Randall needed to be at the hospital on the 8th so he could started with the bone marrow transplant.

We had no time to spare. Henry and I rushed home to get things organized for the trip to Minnesota. As we packed, my mind began to race. We had a stack of bills and no money for airplane tickets. How are we going to do this? Then a few minutes later, the telephone rang. It was an office employee at the Mueller plant where Henry and I both worked. She told me they’d had a drawing at the plant, and that I was the winner of five hundred dollars. It was as if God had a watch and had so perfectly timed the blessing. Henry, our daughters, and I were overwhelmed with joy at this great and badly needed boost. We needed this money to put toward our flight to Minnesota.

We were told that if Randy’s marrow transplant was successful, we would be in Minneapolis for quite some time. It would take a while for Randy to be strong enough to make the trip home.

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As I went through the closet, looking for things to pack, I became increasingly frustrated. Over the past few months, probably due to stress, I had gained over twenty pounds. Now, out of all my things, I only had two pairs of jeans that still fit. I looked over at Henry, who was quickly packing own his suitcase and muttered, "Henry has a lot of nice clothes, and I hardly have any, because I've gained too much weight. I don't have the money or time to shop for new ones now. This will just have to do."

Right after we had finished packing, the phone rang again. This time it was Dr. P, informing us of a change of schedule. As they were still looking for a bone marrow donor, Dr. Wagner had arranged for Randall to fly out on a later date. As we began to unpack, Henry reached for a pair of his pants and a T-shirt from the suitcase and began pulling them on. Or, at least he tried to pull them on. They did not fit. Looking puzzled, he discarded them and tried on other clothes from his suitcase. After several attempts, he discovered that he could not wear one pair of pants and a couple of shirts. His other clothes were all too small as well.

His puzzlement turned to dismay. "I packed all of these nice clothes, and I only have one pair of pants and a couple of shirts that I can fit into. I've gained too much weight!" He looked genuinely surprised. "Luckily Dr. Wagner changed the date for us to take Randall to Minneapolis, because I hardly have anything to wear."

I took one look at him and burst out laughing. "Well, welcome to my world. I hadn't realized that you had gained so much weight too. I guess we've been

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working so hard and worrying so much about the bills that we haven't had a chance to go shopping for ourselves."

In addition to the doctor's nationwide search for a bone marrow match, Henry and I, aided by our community, started campaigning and conducting bone marrow drives in various cities in the surrounding states. About twenty of his male cousins came to the hospital to be tested for a bone marrow match. To the relatives who lived too far away, we sent kits to their home to see if they were a match for Randall. They all wanted to help save his life.

The media met with Randy in his hospital room in Memphis. In addition to the television interviews, the Commercial Appeal did a write-up concerning his health matter, the blood drives, and the benefits. During one television interview, Randy told the media that he was very thankful to all the people who were willing to be tested and become a bone marrow donor. His statement was a testimony to his generous and loving heart.

"If you can't help me, you may be able to help someone else like me. I am nineteen years old, and I have pretty much lived my life. However, there may be a three- or five-year-old kid out there that has never really had a chance at a normal life. You may be able to help them by being a bone marrow donor."

In late January, we received an optimistic call from the doctors in Minneapolis. They had found an umbilical cord match! Randy needed to be in Minnesota on February 9th so they could discuss the next step in person, or he could stay for the transplant. It was not a

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perfect match, but it was a match. They felt comfortable with the match, but Randy did not want to do it. He had been inside his small blue room for four months, and loved the nurses. They had spoiled him. They called him their “baby”. He would watch movies all day, and he tried to walk when he was not too tired.

“I feel good enough to wait for a perfect match,” he told them. “I’m fine.”

“Randall,” I said, “if we thought you were fine, we wouldn’t be here with you every day, we would be working.”

“Mama, quit worrying,” Randall said with a smile. “I told you, I’m fine.”

“Yeah, you’re fine, alright. You can’t even walk!”

“I can to walk!,” he argued.

“No, you can’t. You’re in this bed all of the time.”

“I just like being in my room.”

I wasn’t sure if he was in denial, really concerned about the match, or if he had just given up. Henry and I lay down on a small cot next to Randall’s bed and went to sleep. That night, Randy stayed up until 5 a.m. watching movies, like he usually did.

Henry and I spent as much time as we possibly could with him, but sometimes we would leave to go pull double and even triple shifts at work. Henry had worked for Halstead for twenty-one years, and four of those years was with the new owner, Mueller. At the time, I had only worked at Mueller for two years.

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One Thursday night, Dr. P came by Randall's room to talk to us about going to Minneapolis.

"Why is everyone telling me I need to do the transplant so soon? I feel good. Why can't I wait a few months?"

"You may think you feel good, but the reality is you probably don't have that long to live. The leukemia cells are becoming resistant to the chemotherapy, which can only be given in low doses because of your anemia. It's too risky. If you get an infection before the transplant, you will most likely die."

When he heard this, Randy finally gave in.

"I guess I have no choice but to go to Minnesota," he said, "but I'm still hoping for a perfect match."

Dr. P told us that he could go home that night, but he had to be back at the hospital at 8 a.m. the next morning to receive blood and a platelets transfusion. This was something he needed every few days, or whenever his count was too low.

Henry and I packed up Randall's clothes and took them to the car. Randy sat on the edge of the bed and combed his hair as he waited for us to come back.

"I can't wait to get a haircut," he said, rubbing his head. "I usually wear it real short." As he combed, chunks of hair came out and fell onto the floor. "Oh well," he said, picking it up and taking it to the trash can, "I knew this was going to happen, sooner or later."

I was torn up inside, seeing my son, another son, go through all of this.

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That Thursday night was cold and dark, with a scattering of rain blowing every so often on account of the high wind. After the long ride home, Randy walked inside and flopped down on the couch in the formal living room. He knew that I did not like him to sleep there, but I let him anyway. Besides, when he left for college, his sister Adrian had taken over his room. Laverne's four-year-old son and her newborn baby boy were also at our house when we arrived. Henry picked up the mail, and sat down. He began to start shuffling envelopes in his large hands. He held one up and said,

"This one is a bill from the Methodist University Hospital."

Due to the extensiveness of the treatment required to keep Randall safe, he had to be transported to the University Hospital in Minneapolis by a medical plane. The doctors in Minneapolis said that between the transplant and the follow up period, Randy might be there from three to nine months.

When Randy quit school to be admitted into the hospital, the insurance company had denied him insurance. Henry and I fought their decision, and finally they decided to extend his coverage for one year. After that, we would be on our own. If Randy was frightened, he did not show it.

"I'm not scared," he said with a smile. "Like I said before, if it's my time, there's nothing I can do about it. So there is no need for me to worry about it."

Randy strongly believed that even if he died, Henry and I would carry on. After all, he had seen us bury his three brothers and still manage to go to work

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and care for our other children. He didn't know that while mourned deeply inside, we had locked away the pain for the sake of our son and daughters; it was the only thing we could do. Randall had had enough problems and enough pain, and we did not want to add to his burden. Henry and I had vowed to never let him see us cry, and we had kept that vow for years. In fact, we had kept up this charade so long, I wondered how I would react if we were to lose Randall. I figured I would probably just keep it all inside. I did not know if I had any tears left. As I contemplated all of this, my chest became so tight that I could hardly breathe. My faith was still strong, and I was not angry with God. I was just confused. I thought, "I still smile, I still hope, and now and again, I still pray." I wondered, "How can one family endure so much pain, and why should we have to?" Then, as if the fear had awakened inside of me, I pleaded in silence, "Lord, please don't take this one too! Don't take Randall. He's our last boy. Don't take him. Lord, please don't take him."

The week before, Henry was sitting beside Randall in the hospital room, a phone book in his lap. "I need a celebrity," he'd said, wringing his hands, "I need someone to make people listen." Then he hung his head in his hands. After a few minutes, he looked up at Randall and said, "I don't know what to do. I just don't know."

Randall said, "I'm in God's hands. Whatever happens, just happens. I'm not scared." He knew he was baptized and had accepted the Lord, so he did not fear death. "Mamma, don't worry," he said. "I'm alright."

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The illnesses and deaths of our three other sons had taken a toll on our family in so many ways, including financially. The bone marrow transplant alone was very costly. Once again, we found ourselves being plucked from our normal lives. We started spilling our hearts to anyone who would listen, whether it was doctors, friends, family, or co-workers. We needed information. We needed money. We needed help. Our last son was dying. We did not know what hand God would deal him, but we knew we would be there, no matter what. We took off work to be there with him and make the tough decisions necessary to save his life. This had a terrible drain on our finances, but all we could think about was Randall. We searched for doctors who knew something - anything - about Wiskott-Aldrich and Fanconi Anemia.

I began to think about, how in many ways, our boys were normal - crazy boys jumping and running, catching frogs, and chasing squirrels in the woods. On the other hand, they were always getting sick with stomachaches, mysterious lumps, and high fevers. Adam was the first to die, on April 14, 1992, age eleven; then Henry, Jr., on April 27, 1995, at age fifteen; and then Carl on January 4, 1999, at age ten. Now Randall, at age nineteen, was getting weaker and the doctors were having trouble finding an exact bone marrow match. I just did not know how much more pain I could bear. After Junior and Carl died, I felt like I was going mad, so I spent countless hours every morning, and every night, writing my feelings down in a book. Even back then, I called the journal, "Angels Never Die". I gathered all the boys' photos together and put them in a scrapbook. I

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wanted to have them close to me at all times. They were the pictures of them when they looked normal, as well as the pictures of them at the end; bloated and often in diapers; their fingers and toes split from all of the fluid in their bodies. Henry, who hardly ever showed his emotions, bought a print of a black angel with her wings spread; her hand clasped above her head. Her eyes were closed. She looked so peaceful. Henry cut out a small picture of the three boys and pasted it in the angel's hands.

"Those are my boys," Henry said, touching their pictures. "I've lost three already."

I would often take the scrapbooks with me to visit Randall. In one of my scrapbooks, there was a picture of him standing in front of Junior's open casket. Junior's face was so bloated, you could not see his neck. Randy had his arm resting on the casket, and his mouth curved to form a smile. Now, in his own hospital bed, Randy looked at the picture and said, "I have to be strong, I'm the only boy left."

Chapter 26

The Brave Battle Ends

On February 9, we flew to Minneapolis. Dr. Wagner was surprised to see Randall looking so well; however, his tests showed a different story. Randall's leukemia was uncontrollable. He had a fever and

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infectious sores had developed under both arms. In addition, they had discovered spots on both his lungs. Randy had to be treated with antibiotics, and transfused with white blood cells to fight the infections.

“White blood cells only last approximately six to twelve hours in the patient’s body before they need to be transfused again,” the doctor warned us.

Every time Randall was injected with chemotherapy to fight the leukemia, his condition immediately worsened. Again, Dr. Wagner warned us, “Too much chemotherapy could kill him, but not enough can as well.”

Randy made it very clear to Dr. Wagner that he wanted a fighting chance. “If I die of leukemia, or if I die from chemo, it’s terrible. Please, just don’t experiment on me.”

As he spoke, I sat on the bed and put my arm around Randy’s shoulders, trying to comfort him. He took my arm from around his shoulder, and instead put his arm around mine. “Mamma this is just a test,” he said, his face peaceful. “I pray to God every night. I have faith in Him. You and Dad don’t need to worry about me; I’m going to be all right.”

Unfortunately, by this time, his body was wracked with pain. His bones were aching and his kidneys were failing. The leukemia was winning. The doctors told Randall that he had two options. He could go back home to Wynne and make the most of what time he had left, or he could stay and fight with the hope that his body could hold out until an umbilical cord blood transplant was available.

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"I know what it's like to die," Randall told Dr. Wagner. "I've seen my brothers die, and I want to keep fighting. I'd rather die trying than not try at all. I don't have anything to lose. I want the chemo, because at least then I have a chance." As he spoke, his nose was bleeding profusely.

Every day, he was extremely thirsty and void of an appetite, but his mind was still strong. Dr. Wagner explained to him that his body was extremely weak, and that he needed to be placed in ICU to have round the clock care.

"Umm," Randall said, in a weak but brave voice, "You know that sounds more like eternal life to me".

Even with my shattered heart, I had to agree. "Yes," I said to him and Dr. Wagner, "it sounds more like eternal life to me as well."

The morning of Wednesday, March 3, Randall was admitted into ICU. He knew his time was short. He was very weak as he asked his dad to call Kristie. Henry dialed the number, then held the phone to Randall's ear. "I love you, Kristie," he whispered. Then he asked, "Do you hear me? I will always love you!" He tried to speak louder, but he could not.

After the call, Kristie immediately boarded a plane for Minneapolis. Unfortunately, she arrived at the hospital thirty minutes too late. Randall had already passed away. He just closed his eyes and went to sleep, never to open them again. He went so quietly, and so peacefully. Afterward, Henry left Randall's room and joined me in the ICU waiting room. He sat down beside me and held me in his arms as he told me that our son

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had died. My mind was numb, but I felt my heart was going to stop. I remembered how Henry used to call him a “mommy’s boy” because I spoiled him so much. He was my only remaining son, I had to spoil him. Now he was gone too. I tried to stand up and walk to the room, but I was so dazed I thought I might faint. As with my other sons, I had tried to prepare myself for this moment, and again it was impossible. Comprehending it after the fact was equally futile. Henry and I had envisioned him growing old, with a nice home and family of his own, but I guess God had something different in mind for our Randy.

We gave Kristie the news when she arrived. She walked with us into the room to see Randy before making the necessary arrangements to take him home. His stiff body lay on the hospital bed, with a white sheet pulled all the way up from his feet to his armpits. The sheet was folded down and across his shoulders, so we could see his face. Despite his wish that we all stay strong, there was no holding back the tears. After a few minutes, we left the room so Kristie could have some time alone with him. We could see her constantly wiping the tears from her eyes. She did not want to leave his side, a feeling we understood all too well.

Henry called our daughters back in Wynne and told them the sad news about their brother. We knew they were just as devastated as we were, but fortunately God had given them the strength they needed to handle his death.

As soon the undertaker had taken his body away, we packed our things and made the preparations for the

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trip back home. On the flight, Henry, Kristie, and I discussed how Randall had fought a good fight, and that he tried to get better so he could have the transplant. He had nearly made it. He was right at the door, and then another one opened.

Randall's funeral service was held on Friday, March 12, 2004. He looked so peaceful and comfortable as he lay at rest in his casket, a mix of shades of green. After the service, he was buried in Paradise Garden Cemetery, beside his brothers.

Someone, I am not sure who, wrote a tribute to Randall and passed out copies at his funeral. Under his picture was written:

"To my parents, Henry and Gwen McNutt, the author and co-author of 'Angels Never Die,' I give you, with unselfish love, the final chapter. This book was created with love from within the hearts of my sisters, Adrian and Laverne, and from the memories of my three brothers, who have all gone before me. I too shall live within. Do not cry for me, as I must leave you for a while. Please do not grieve or shed wild tears. Instead, start out bravely with a gallant smile for my sake, and in my name, live on and keep all things the same. Feed not your loneliness on empty days, but fill each working hour in useful ways. Reach out your hand in comfort and in cheer, and I in return will comfort you and hold you near; and never, never be afraid to die, for I am waiting for you in the sky (Where ever the place is that God have prepared for us)."

It was one month after Randall's death, and Laverne's birthday. That night, I fell asleep and had a

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dream that Randall came home, dressed in a white suit. He looked, acted, and talked normal, but he was a spirit, an angel that had come to comfort us and give us peace of mind. I asked him if he was here to stay. He answered with a very gentle voice, “ I don’t know exactly how long I’ll be here with you, but I do know that it will only be a little while, then I’ll go back to where I came from. Nobody can hear or see me except my family.”

Seeing him, even in a dream, brought so much joy to my heart, just as he always brought us so much joy when he was alive.

Chapter 27

Precious Memories Of Randall

Randall was a gentle and sensitive young man who loved reading the Holy Bible, especially from the Book of Revelation. He was always concerned about others and never wanted to see his family worry about anything. Yet, as each birthday approached, he would ask, “Will I reach the age of twenty-one?” At eighteen, he said, “I am very close, but my disease may not let me get there”.

I once told him, “Don’t worry about your condition, and just make each day your best, because no one knows how long they will be here on this earth. There have been so many people who were not sick or hospitalized, but were taken suddenly. God is in control.

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We are in His hands, and people die whenever He is ready for them. Whatever God's will, it shall be done, good or bad. I am sure that God can still keep us strong and help us to bear the pain."

Randall and Adrian had always had a very close relationship. Whenever he came home from college, he loved to aggravate her by kissing her on the cheek. She would fight him off as he laughed. They sat up many nights talking and sharing opinions with each other about things that had happened at school or other matters. One time I walked into the room during one of their conversations and heard Randall say to Adrian, "If I ever die, I am going to spook you really good, and am going to make you think that you've lost your mind."

I burst out laughing.

"Stop playing, Randy," Adrian said, but she was laughing too.

Since Randy's passing, Adrian has often told me about strange occurrences that she feels may be Randall trying to let her know that he is there.

Randy touched everyone. We all miss his warm smile, his hugs, and his kisses. Laverne's son Allen was only four when Randy passed away, yet he remembers and misses him. "I want to see my Uncle Randy again," he often says.

Kristie still wears the engagement ring that he gave her, and she still visits with us at our home. Randall and Kristie would often daydream about getting married and having a bunch of kids of their own. It just was not in God's plan.

Chapter 28

In Conclusion

I am so grateful for every moment I've had with my children. Today, when I think of my four boys, I think only of the good times, and the joy they brought to our hearts. I also think about what I have learned from them over the years. I have learned that my children were - are - the strong ones. My boys were incredibly brave to have faced all they did in their short lives. My daughters, God praise them, allowed their brothers to have the necessary attention during their illnesses, thus becoming shadows during their despair. All my children have shown so much strength throughout it all. They have been, and always will be, the foundation for my faith.

My husband, Henry, is the rock I could not have lived without. We have shared so much together, both good and bad, and God could not have picked a better person for me to share my life with. I am eternally grateful for Henry to have come into my life.

I am also grateful to all the other family and friends who supported us during those grueling years. The community came together and gave us the strength to go on, even when we were going through the worst of the worst.

Life is about death – how we handle it, and the secret to living. To live means to understand that death

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is a part of life. As in birth, death brings us together. It unites us in a way that is without words. Death creates a bond for the living that cannot be broken. It makes us stronger, resilient, patient, and gives us the ability to love even more. We will all face death when it is our time.

To lose a child is truly one of the most devastating things we can face as human beings. However, to accept that death as a blessing for having lived is the only way we can move on with our life. It is the memories we make before death that will never die. We will hold them in our minds, our hearts, and in the images taken before they left this earth. I would not trade my life for anything. I cherish every moment I had with my boys, including their illnesses. God blessed me with their presence, and for that, I am forever thankful, no matter how trying or short it may have been. Their faces are forever etched into the memory of my soul.

I constantly look for their spirit in every living thing; whether at the park, in the store, or watching television in the comfort of my own home. When I see a rabbit hop across the lawn, I envision how curious they would have been, looking out the window, or at night when I see a fire fly outside, I envision the boys catching them in a jar. When I look out my back window, I can still see Laverne, Adrian and the boys all playing together in the yard. Their spirits are forever a part of me.

I have learned that life is all about perseverance. That no matter what, we must go on for those that live

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on with us. Perseverance is what keeps the memories of those that have past alive.

Then there is faith – faith is the one thing that holds it all together. Faith is the foundation upon which we build our souls. Without it, we are lost. I have learned to have faith in all we do. I have learned the importance of having faith in family, friends, community, and belief. Faith unites us as a people and a nation. Without faith in mankind, we would just be lost and wandering souls. We all need something to cling to, something to hold onto, something to believe in, and something to get us through the worst of times. Faith is the glue that binds us as human beings. My children have taught me that faith is unwavering, that it is always there in the human spirit; you just have to find it. Moreover, through all the trials and tribulations I have endured, my faith in God is as strong as ever, and despite my grief, I take pleasure in knowing my sons now walk with Him.

All of our boys have left us in the flesh, but they will never leave us in the spirit. They are always close to our hearts. *“And God shall wipe away all tears from their eyes; and there shall be no more death, neither sorrow, nor crying. Neither shall there be any more pain: for the former things are passed away,” (Rev. 21:4).*

HOW IS FANCONI ANEMIA DIAGNOSED?

Scientists believe that Fanconi anemia is under diagnosed. The reason is obvious: FA makes its first appearance in countless different ways. Some babies are diagnosed at birth. Others may grow into adulthood before discovering they are affected by FA. Still other FA patients are never correctly diagnosed. Efforts are underway to educate doctors in various medical specialties about the kinds of symptoms and signs that may indicate FA. Currently, most tests for FA involve taking a small sample of blood from the patient and combining the blood's lymphocytes (a type of white cell) with chemical agents such as diepoxybutane (DEB). In the laboratory, the chromosomes within the FA cells break and rearrange under the influence of these destructive agents; the chromosomes in normal cells are more stable at the same level.

By using these tests, performed in highly skilled laboratories, suspected cases can be confirmed. These tests are absolutely essential to establishing an FA diagnosis, because the clinical features of many different diseases so closely resemble FA.

The chromosome breakage test should also be performed on other siblings in a family where an FA patient is diagnosed. Even normal-appearing brothers and sisters may have the condition. If your family is considering a bone marrow transplant from a family member, it is crucial to test for matching tissue types.

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FA can be diagnosed even before a child is born. The diagnosis can be made based on a chorionic villus sampling (CVS), performed in the 10th to 12th week of a pregnancy, or by amniocentesis, performed most often in the 15th to 17th week of pregnancy. The diagnosis of FA in a child has led to the testing of brothers and sisters. Those tests may demonstrate FA, even if the sibling presently is healthy, shows no birth defects and has normal blood counts. (Lynn and Dave Frohnmayer, *Fanconi Anemia A HAND BOOK FOR FAMILIES*. Pg. 5-6

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